AN INTERVENTION DESIGNED TO REDUCE STRESS IN MOTHERS OF
CHILDREN UNDERGOING BONE MARROW TRANSPLANTATION

BY

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Decreasing parental stress resulting from children's painful and long-lasting

medical ordeals has been a largely unaddressed but important area in the psychosocial

literature. Only a small number of experimental studies aimed at managing the stress of

parents under these circumstances have been reported. While one such study has focused

on parents of children with cancer, no known studies have specifically explored

decreasing stress in parents of children undergoing bone marrow transplantation (BMT).

The present study focused on reducing mothers' distress while their children were

inpatients on a bone marrow transplant unit (BMTU). A new program hypothesized to

better prepare parents for BMT was specifically designed to decrease parents' stress

associated with their children's lengthy inpatient stay. Participants were randomly

assigned to either the intervention or the currently used standard preparation procedure. Dependent variables included parental stress measured through several self-report measures and a semi-structured interview, as well as number of intervention strategies used, coping style, and major life events.

The purpose of this study was to investigate the efficacy of this intervention compared with the standard procedure for preparing parents and families before a BMTU admission. It was hypothesized that parents in the intervention condition would report lower levels of stress compared to those participants in the standard preparation condition. Participants were 22 parents of children who underwent BMT at Shands Hospital at the University of Florida. Participation was voluntary.

Results indicated limited support for the efficacy of the intervention, with only a few noted differences between the two groups. Findings were significant for changes in stress over time, with participants reporting significantly greater stress on 3 different measures of stress at pre-admission than during their child's hospitalization. Several methodological concerns are noted and overall suggest the need for further investigation prior to making definitive statements about the efficacy of the current intervention. Clinical implications include the importance of assessing parents' stress and coping prior to child's admission in order to determine the need for intervention. Interventions focusing on pre-admission rather than hospitalization stressors will likely be most beneficial to parents.

INTRODUCTION

Chronic illness in childhood can potentially alter many aspects of family functioning. Through the illness experience, families often encounter a variety of stressors. Such stressors can impact the child and family in multiple ways and may result in spousal conflict, financial strain, increased behavior problems, poor overall competence, low self-concept, uncertainty about the future, and increased family stress. Furthermore, families are impacted by the illness itself and may demonstrate emotional difficulties related to acceptance of diagnosis, and/or ineffective coping strategies for handling illness-related tasks (Kazak, 1989; McDaniel, Hepworth, & Doherty, 1992; Turk & Kerns, 1985).

Increased levels of stress have reportedly been associated with a variety of medical disorders, and the role of stress in adjustment to illness or invasive medical procedures continues to be examined. In studies which have specifically examined the role of stress in medical procedures, children have been found to display stressful symptoms, as have their family members (Dahlquist, Power, & Carlson, 1995; Frank, Blount, Smith, Manimala, & Martin, 1995; Hughes & Lieberman, 1990; Jay, Ozolins, Elliott, & Caldwell, 1983; Stuber Nader, Yasuda, Pynoos, & Cohen, 1991). As such, a variety of interventions have been designed to alleviate stress in children undergoing invasive or painful medical procedures (Campbell, Kirkpatrick, Berry, & Lamberti, 1995; Jay, Elliott, Katz, & Siegel,

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1987; Meng & Zastowny, 1980). Although parents experience significant stress from their child's illness, only a handful of studies have focused primarily on alleviating stress in parents themselves (Campbell et al., 1995; Jay & Elliott, 1990).

In comparison to adjustment to other chronic medical conditions, less information specific to psychosocial adjustment in pediatric BMT is available. Until the last several decades, many children with common types of cancers had little chance for survival. However, with the advent of BMT, increasing numbers of children are surviving. Although many successful transplants have been performed on a variety of cancerous and non-cancerous disorders, the decision to undergo BMT continues to carry with it some level of uncertainty. Due to the rigorous physical sequelae of BMT, some patients die prior to being discharged from the hospital. Overall, the decision to pursue BMT is typically a very difficult one faced by families.

Children with cancer who undergo BMT may encounter some of the aforementioned general stressors related to childhood chronic illness, yet several aspects of BMT make the experience unique. For example, children undergoing BMT have often withstood painful and invasive procedures as part of earlier treatment regimens. Children and families must endure a lengthy hospitalization which is typically in a setting far removed from home. BMT also requires the child to remain in an isolated room while on the BMTU, limiting or eliminating contact with friends and/or siblings. Furthermore, multiple restrictions (e.g., avoiding crowded places, little contact with animals or plants) after discharge must also be adhered to in order to decrease risk of infection.

Although there have been only a limited number of studies examining the particular psychosocial impact of pediatric BMT, results from such work, coupled with our knowledge about chronic illnesses in general, suggest that BMT is a highly stressful time for both children and their families (Lee et al., 1994; McConville et al., 1990; Phipps et al., 1995; Sormanti, Dungan, & Rieker, 1994; Stuber et al., 1991; Wiley & House, 1988). However, no known previous studies have specifically been designed to examine the effectiveness of interventions to alleviate stress in parents of children undergoing such treatment. As BMT has been indicated as a long-term, stressful time for both children and their families, it was considered worthwhile to investigate an intervention program to help parents better prepare for, and effectively cope with, BMT.

Topics discussed in the following literature review include family adaptation to childhood chronic illness, theoretical models of stress and their application to childhood chronic illness, interventions aimed at decreasing parental stress, and medical and psychosocial aspects of BMT.

<u>Family Adaptation to Childhood Chronic Illness</u>

Turk and Kerns (1985) define a family as a group composed of members who have mutual obligations to provide a broad range of emotional and material support to one another. Within childhood chronic illness, families are important to study for several reasons. First, families are often the most effective mediators of change. After an event takes place (e.g., intervention, hospital stay, or outpatient treatment), the family continues to be responsible for coping with the situation, and therefore mediating the change (Fiese & Samaroff, 1989). Second, there are multiple causes of any particular behavior and the

family must be examined within an ecological context, as all family members participate in shaping individual members' behavior (Fiese & Samaroff, 1989; Kazak, 1989).

When childhood chronic illness is included in the family environment, the family must make several adaptations to adequately cope with the various demands. For example, the detection of a chronic illness often means that the family must make a lifelong commitment to typically complex, expensive, and often painful procedures in order to ensure the management of the illness (Turk & Kerns, 1985). Parents may try to manage or help the child accept and cope with the realities of the illness, while at the same time help him or her to develop as normally as possible. Furthermore, parents attempt to accomplish this without disrupting the family's everyday functioning. Issues that families may encounter include parental guilt, grief over loss of a "normal childhood," developmental obstacles, and uncertainty about the future (Turk & Kerns, 1985; McDaniel, Hepworth, & Doherty, 1992). Other more general stressors that are likely to affect families include finances, hospitalization, restriction of physical activity, interruption of peer activities, and absences from school.

Various family models have been utilized to describe behavior within families in which a child has a chronic illness. A systems perspective explains how families balance periods of change and stability while always leaning toward homeostasis (Turk & Kerns, 1985). More recently, the systems perspective has been expanded to incorporate social-ecological theories relevant to children with chronic illness and their families. A social-ecological perspective examines all systems which may affect, or be affected by, the child. For example, a child's school, his/her community, as well as societal values, are

taken into account through the use of this perspective. The child is seen as being at the center of a series of concentric circles which illustrate the bidirectional influences on the child (Kazak, 1989). Kazak highlights the importance of utilizing a social-ecological perspective in order to best explain the ways in which a child and family cope with, and adapt to, illness.

Similar to Kazak's (1989) social-ecological perspective, the Double ABCX model (Patterson, 1988) has also been used to describe the ways in which a family adjusts and adapts to stressful experiences. McCubbin and Hill's model incorporates the variables of change within the family system (A), family resources (B), family definition and meaning of the stressor (C), and family adaptation or crisis (X). The family attempts to maintain balanced functioning by meeting its demands and using its resources. The meaning that the family gives to the demands, coupled with the family's perception of its capabilities for coping with them, is paramount in achieving balanced functioning (Patterson, 1988). In a literature review integrating childhood chronic illness with family systems approaches, Hare, Skinner, and Kliewer (1989) suggest the use of the Double ABCX model in examining family response to pediatric BMT. The authors indicate that how families define the demands involved with BMT leads to either acceptance and adjustment, or crisis.

Fiese and Samaroff (1989) have proposed a transactional model of family stress and adjustment. Major tenets of their theory state that the chronically ill child is a dynamic system which is maintained by bidirectional influences between the child's and family's behavior. The family is thought of as having a code which suggests expected

behaviors of the child and family in a variety of circumstances; the family and child are thought to strive towards an adaptive state of interaction by engaging in a series of transactions between the child's behavior and the family's code. Fiese and Samaroff suggest that at times, a family's code must be altered in order to reach a state of adaptation, or to allow for differing expectations. For example, if a sports-oriented couple were to give birth to a child with cystic fibrosis, the family code related to physical activity would need to be altered to include a child who does not have the capabilities to excel in all athletics.

Wallander and Varni (Wallander et al., 1989) have proposed another model of family adaptation involving children with illnesses. In the Disease/ Disability Stress Coping Model (DSC), risk and resistance factors mediate a child's and parent's adaptation. Risk factors include disease parameters, functional independence, and psychosocial stressors; resistance factors include intrapersonal factors, social-ecological factors, and stress-processing variables. Risk and resistance factors from Wallander and Varni's model, as well as other family functioning or adaptation variables, have been studied within the context of a variety of chronic illnesses including cystic fibrosis, diabetes, juvenile rheumatoid arthritis, and cancer (Chaney & Peterson, 1989; Kazak & Meadows, 1989; Walker, Ortiz-Valdez, & Newbrough, 1989).

In a longitudinal study of 64 families with children newly diagnosed with cancer, Kupst (1992) found that most families appear to be functioning within the normal range on standardized instruments approximately seven years posttreatment. Families were assessed at several times, beginning pre-treatment. Kupst found coping processes to be

variable both within families and over time. She also found mothers' coping to be important in modeling coping behaviors for children. In a more recent report, the same cohort of children and families continued to do relatively well 10 years posttreatment (Kupst et al., 1995). The relationship between mother's and children's adjustment seen at seven years post-treatment was also found at 10 years post-treatment.

Although Kupst et al. (1995) found families to be coping fairly well posttreatment, in a recent study by Kazak et al. (1997), parents of children who had finished treatment for childhood cancer at least one year previously were found to have higher rates of PTSD than parents in a comparison group of parents of healthy children. The study of Kazak et al. examined the revision of DSM-IV to include life threatening illness of a child in the diagnostic criteria for PTSD. Children's responses were also investigated and no differences in rates of PTSD were found between cancer survivors and healthy controls. Their results illustrate the importance of considering parents' functioning when working with these children.

Birenbaum (1990) described parents' coping strategies in 45 families with a child with cancer. Findings revealed families to be coping relatively well. Using the Coping Health Inventory for Parents (CHIP), Birenbaum explored the addition of two dimensions using selected items from the CHIP: encapsulation and at-risk. She defines encapsulation as including such topics as normalization of the illness and controlling the meaning of the experience of the illness. At-risk is thought to include adhering with treatment, and protecting the child. Birenbaum hypothesizes that while encapsulating the illness may benefit the family, using at-risk behavior may deplete the family's energy for coping with

the illness. Birenbaum's use of the two new scales was not empirically derived, nor were the scales substantiated through the use of statistical analyses. This investigation is one example of the less than rigorous methodology that is often employed within the area of childhood chronic illness.

Several studies examining children's adaptation and adjustment related to family variables have also been conducted. In a study aimed at comparing adolescents who had survived cancer and adolescents without an illness history, Kazak and Meadows (1989) found no differences between the two groups on measures of psychological and social functioning. However, overall competence in these children was related to both family rigidity and adaptability, with children in less rigid and more adaptable families illustrating higher levels of competence. In another investigation of family characteristics and childhood outcome, adherence in children and adolescents with juvenile rheumatoid arthritis (JRA) was examined. Chaney and Peterson (1989) concluded that increased family stress was related to poor adherence to treatment regimen, and children in families with lower levels of cohesion and adaptability were found to have poorer overall functioning.

As indicated in Wallander and Varni's DSC Model (1989), socio-ecological characteristics of a parent may influence coping with chronic illness. Walker, Ortiz-Valdez, and Newbrough (1989) studied the role of maternal employment and depression in reporting of behavior problems in chronically ill, mentally retarded, and healthy children. Mothers who were employed were found to have lower levels of depression. Unemployed mothers, with higher levels of depression, reported higher frequencies of

behavior problems in their children. The authors suggest that childhood illness is typically an uncontrollable factor in families' lives, and employment may offer mothers the opportunity to gain some control. Likewise, Walker et al. suggest that employment may allow mothers to feel a sense of accomplishment. It is important to keep in mind, however, that employment opportunities may not be available to mothers who must be full or part-time caregivers for their chronically ill children. This study highlights the importance of assessing family members' psychosocial adjustment, rather than focusing solely on the child with the chronic illness.

In a study similar to the one conducted by Walker et al. (1989), Canning, Harris, and Kelleher (1996) examined factors considered to be predictive of distress among caregivers of chronically ill children. Parents' report of impact or burden, in addition to their income level, was found to be most predictive of distress; the child's actual medical condition was not related to parents' distress.

Parents' experiences during and after a child's hospitalization on a Pediatric Intensive Care Unit (PICU) were examined by Youngblut and Shiao (1993). They studied nine mothers and fathers of children under the age of five who were on a PICU and who were expected to survive. Parental distress was measured 24 hours after admission and again 2-4 weeks after discharge. Using data gathered from several parental self-report and family measures, the authors concluded that the PICU hospitalization was a stressful time, independent of illness severity. However, mothers' ratings of family cohesion and satisfaction with the family post-discharge were negatively correlated with the amount of time that the child had been intubated on the PICU. This

finding suggests a relationship between mothers' perceived illness severity and perceived distress, with mothers who perceive their children to be at greater risk reporting more significant distress in themselves and in their families.

Marital satisfaction is another aspect of family functioning that has been explored within the context of general childhood chronic illness, as well as specifically within families with children with cancer. Although some studies have found lower marital satisfaction in such couples, other studies have actually indicated lower rates of divorce (Dahlquist et al., 1993). Furthermore, studies of families with children with cancer have found both increases and decreases in marital satisfaction after initial diagnosis. Thus, the data are equivocal in this area. However, Dahlquist et al. improved upon past literature by examining coping style and marital distress in parents of children newly diagnosed with cancer by using a standardized assessment. Marital satisfaction, distress, and parental anxiety and depression were assessed in 67 pairs of parents. Results indicated that approximately one-quarter of both the mothers and fathers were experiencing significant marital distress. Increased marital distress was found to be associated with greater differences between spouses' anxiety levels. The authors suggest the importance of examining the strength of the marital relationship when attempting to understand the impact of a child's illness on the family. In a similar study, Walker, Manion, Cloutier, and Johnson (1992) also found parents of chronically ill children to exhibit significant distress.

As part of the family system, healthy siblings can also be affected by childhood illness. Similar to findings from the marital satisfaction literature, research with siblings

of ill children has also been inconclusive, with some researchers finding healthy siblings as benefiting from the experience of having a chronically ill sibling (Lobato, Faust, & Spirito, 1988), and others describing possible difficulties in the sibling relationship (Freund & Siegel, 1986). Lobato and her colleagues suggest that illness and family variables mediate how siblings will be affected by illness in the family. For example, if siblings are able to develop a relatively strong relationship prior to the onset of the illness, the sibling is thought to be more likely to be better adjusted. In contrast, when the healthy sibling is younger than the child with the illness, he or she may be asked to take on responsibilities out of the ordinary for his/her development or age, thereby putting additional pressures on the healthy sibling.

Overall, families with chronically ill children undergo many changes in their attempt to adapt to the child's illness, and research has indicated that how the family adjusts to a child's illness may change over time (Kupst, 1992). Family models account for bidirectional influences on the child and family (Fiese & Samaroff, 1989), parent-related variables which may influence family adaptation (Wallander et al., 1989), and influences from other areas such as the child's school and the community (Kazak, 1989). Furthermore, the family's adjustment may be related to family variables (e.g., adaptability and cohesion; Chaney & Peterson, 1989), or how stressed individual members of the family view themselves as being (Walker et al., 1989; Youngblut & Shiao, 1993). Taken together, such findings indicate the many variables which must be considered when contemplating the effects of chronic illness on a child and his/her family.

Stress: Theories, Measurement, and Reduction

Stress can be conceptualized as a stimulus (external event), as a response (internal event), or as a transaction between the external and internal events (Bernard & Krupat, 1994; Johnson, 1986; Lazarus & Folkman, 1984). In 1952, Canon described stress as an emotional or physiological event, suggesting that stimuli (e.g., natural disaster, death of a loved one) are inherently stressful, and can disrupt one's homeostasis (Bernard & Krupat, 1994). According to physiologist Hans Selye, stress is a nonspecific emotional or physiological response to an external stimulus; individuals react similarly to various stressors (Lazarus & Folkman, 1984). Lazarus and Folkman's theory states that stress occurs only after a transaction between the environment (stimulus) and person (response) has taken place. They define stress as a personally relevant, potentially dangerous relationship between the person and environment which is appraised as taxing or exceeding one's resources. Unlike Selye's and Canon's theories, Lazarus and Folkman's transactional theory of stress takes individual variability into account.

Stressors and stress responses vary in both type and duration. There are major life events which affect many people and those which affect few or even one person. Daily hassles are another type of stressor and are characterized by minor irritants that may occur daily. Duration of stressors can be acute, time-limited (medical procedure), sequential (bereavement), chronic intermittent (difficulty with one's in-laws), or chronic (chronic illness, or difficulty at one's place of employment) (Lazarus & Folkman, 1984). As explained in Lazarus and Folkman's transactional theory of stress, the mere occurrence of such events is not sufficient for stress to occur.

Cognitive appraisal is the means by which the determination of stress is made. Primary appraisal occurs after a stimulus triggers an individual to question if he/she is in trouble or is being benefited, and in what ways (Bernard & Krupat, 1994; Johnson, 1986; Lazarus & Folkman, 1984). Stimuli are appraised as either irrelevant, benign-positive, or stressful; stressful circumstances include damage which has already occurred, damage which is anticipated, or even a challenge or potential for gain and growth.

Secondary appraisal occurs after a situation or relationship has been determined to be stressful. At this point, the individual asks him/herself what, if anything, can be done about the situation. The secondary appraisal component of Lazarus and Folkman's theory incorporates aspects of Bandura's theory of self-efficacy (Bandura, 1977; Lazarus & Folkman, 1984). Secondary appraisal determines how one will cope with the stress and overall takes into account available coping options, the likelihood that one will be able to apply a particular strategy in an effective manner, and the likelihood that the given option will accomplish what it is intended to.

Stress can be measured at the physiological, psychological, and sociological level, and the experience of stress at one level does not ensure that it will be felt at other levels (Bernard & Krupat, 1994). On the psychological level, stress can be measured through observation (Campbell et al., 1995; Jay et al., 1983) or by self-report. Self-report measures of stress generally fall into one of two categories: major life events and daily hassles. Major life events scales differ in their assumption of individual variability. Some questionnaires do not ask respondents to rate the events as either positive or negative, thereby intimating that change alone is stressful (Johnson, 1986). Other scales

incorporate individual variability and ask the respondent to indicate valence or rating of events.

Measures that assess daily hassles typically ask the respondent to indicate the occurrence of daily living events that one may consider to be stressful (unable to meet a deadline, fight with significant other). Research has indicated higher correlations between measures of daily hassles and stress and illness than major life events and stress and illness (Cohen & Williamson, 1991; Johnson, 1986). Furthermore, measures of life events may be more appropriate in cross-sectional versus longitudinal research, where measures of daily hassles are likely to yield more variability over time.

Efforts at reducing stress have included relaxation training, modifying cognitive processes, and stress inoculation. Based largely on the transactional model of stress (Folkman & Lazarus, 1984), stress inoculation encompasses cognitive processes as well as relaxation and behavioral principles. Stress inoculation can be designed for completion in one or multiple sessions, and has been successfully used with a variety of populations including various phobias and test anxiety (Meichenbaum, 1976). Several studies attempting to decrease stress in chronically ill or handicapped children and their parents have also utilized such an approach (Jay & Elliott, 1991; Singer, Irvin, & Hawkins, 1988). According to Meichenbaum (1976), stress inoculation consists of both in-session training and homework assignments, and three main components must be present for stress reduction to be maximized: (1) elucidation of various stressful reactions, (2) training and rehearsal of relaxation and self-instructional coping skills, and (3) practicing the new coping skills under stressful situations. When stress inoculation is

successful, cognitive redefinition is thought to have successfully altered one's appraisal of stress. The individual has managed the previously stressful situation by either changing the actual stimulus, distracting him/herself from it, or by altering his/her appraisal of the stimulus (Bernard & Krupat, 1994).

<u>Interventions Designed to Decrease Stress in Parents of Chronically Ill Children</u>

Reviews of the literature on preparing children and families for both painful medical procedures and hospitalization suggest the importance of parent participation in interventions (Melamed & Ridley-Johnson, 1988; Patterson & Ware, 1988). Findings have revealed a positive association between parental anxiety and child distress exhibited during medical procedures; prepared parents were more likely to have children who were less anxious and less distressed. Suggested implications include better preparation for highly anxious parents in order to assist the child in the stress management process and instructing all parents in ways in which they can both decrease their stress and anxiety and better help their child to cope.

In another review of approaches to help parents and children cope with medical procedures, Hunsberger, Love, and Byrne (1984) cited three important objectives: (1) provide information to the child and family to familiarize them with the environment, (2) provide emotional support and develop a trusting relationship between child and parents, and (3) assist the child in gaining a sense of control. Providing information includes sensory and procedural information using a coping versus mastery modeling technique. The trusting relationship between child and parent emphasizes the importance of communication within the family, and gaining a sense of control includes such techniques

as progressive muscle relaxation (PMR), imagery, and systematic desensitization. The authors indicate the importance of considering the child's developmental level, as well as currently used coping strategies in determining appropriate preparations.

In one of the earliest studies to include parents in preparation or stress management procedures, Wolfer and Visintainer (1979) divided 163 families into five different types of preparation for children's tonsillectomy. Groups included combinations of home preparation with different types of in-hospital preparation and supportive care. The part of the intervention which included parents utilized a preparation book which had detailed information about hospital routines, policies, events, and procedures; roles of various personnel; range of childrens' possible responses and feelings; and suggestions on how the parent could prepare the child. The authors found children in the home only or home and hospital preparation to have better adjustment, and parents who received some in-hospital preparation to have higher levels of satisfaction and less anxiety than those who received home only preparation. Although these findings further support the importance of preparing both children and parents, the outcome measures were not standardized, suggesting the need for continued research.

In a stress management program for parents of children with severe handicaps (e.g., mental retardation, autism, cerebral palsy), Singer, Irvin, and Hawkins (1988) designed a training program for 36 parents. Participants attended two-hour weekly sessions for 8 weeks which included self-monitoring of stressful events, PMR, and modification of cognitions associated with distress. Sessions involved 8-10 participants at a time, and followed a format of lecture, demonstration, discussion, and assignment of

homework. Compared to a control group of untreated parents, participants in the stress management group had significantly lower levels of anxiety posttreatment. Although this study focused on adaptation to stressors associated with a handicapped child, generalizations to more discrete events such as hospitalization can be considered.

In developing a presurgical preparation program, Robinson and Kobayashi (1991) randomly assigned children undergoing elective surgery to one of three conditions: providing information through filmed modeling only, providing information through filmed modeling and coping skills training for children, or all treatment components with the addition of parent coping skills training. The authors measured differences in child and parent anxiety through both self-report and observational measures designed for use in their study. No differences between the three groups were found, with all participants having lower levels of anxiety post-intervention. Outcome measures were designed specifically for the particular study, and had not been previously standardized. Therefore, results should be interpreted with some caution. Results are also somewhat inconclusive, given that the authors did not include a no-treatment or standard preparation control group.

In another intervention designed to reduce distress in parents and children undergoing elective surgery, Zastowny, Kirschenbaum, and Meng (1986) examined 33 parent-child dyads prior to, during, and following hospitalization. Parents and children were stratified on several demographic characteristics and then randomly assigned to either the information only, information and anxiety reduction, or information and coping skills training group. Parents were the primary recipients of the intervention, yet children

remained in the room at all times. Three to six families were seen together for one session, approximately one week prior to hospitalization. The information component consisted of filmed modeling. The anxiety reduction group watched a short video on the conceptualization of stress which was followed by a lecture on ways to reduce stress. The coping skills component included a video on the conceptualization of stress and the use of coping skills. Parents in the coping skills group also watched a video which modeled a parent helping his/her child cope with the surgery. Compared to the information only group, the anxiety reduction and coping skills groups had lower levels of children's self-reported fearfulness and parents' reported distress. In addition, children in the coping skills group exhibited fewer negative behaviors during hospitalization. Given the use of satisfactory methodological standards, results suggest that preparation beyond the dissemination of information is beneficial to both children and parents in children undergoing elective surgeries. This finding is particularly noteworthy given that standard practice for most hospitalizations or surgeries consists primarily of the dissemination of information related to procedures.

Parents were included in a preliminary investigation of the impact of parent-administered hypnotherapy on reducing behavioral distress in children undergoing endoscopy. Young and Schnee (1997) divided 53 children into three groups: standard medical treatment, hypnotherapeutic intervention, and counseling. Parents participated with their children in each of the three groups, yet it was in the hypnotherapy intervention group that parents were trained to coach their children through the uncomfortable procedure. Although the authors hypothesized children in the hypnotherapy group to

have less observed and reported distress during the endoscopy, no differences were found between treatment groups. Young and Schnee concluded that children's distress was associated with parental distress and reaction, and that parents appeared to need more training in the intervention than they might have received.

Given the relatively few interventions that have been designed for complicated surgeries or seriously ill children, the interventions described thus far have focused largely on minor or elective medical procedures. In a procedure with children who were more seriously ill, parents and children were both included in a stress management training program for children undergoing cardiac catheterization (Campbell, Clark, & Kirkpatrick, 1986). Twenty-six children with congenital heart disease were stratified on age and then randomly assigned to either a control or treatment group. The control group received a brochure which described the surgical procedure in detail. The experimental group was a three session stress management intervention which included supportive counseling, PMR, breathing, self-hypnosis, biofeedback, and cognitive reframing. Parents learned the skills, watched the therapist use the skills with the child, then practiced the skills in an imagined scene. Using both parent and child self-report measures as well as observation, children in the intervention group were found to be less upset, and exhibited more cooperative behaviors than children in the no-treatment control group. Furthermore, using structured interviews, parents in the intervention group reported themselves as being less stressed.

In an attempt to prepare children with congenital heart disease for a more invasive procedure, Campbell, Kirkpatrick, Berry, and Lamberti (1995) followed 48 child-

caregiver dyads in children undergoing cardiac surgery. Two weeks prior to surgery, parents and children in the no treatment group received the standard information given to families undergoing the procedure. Such information was also given to children and parents in the intervention group. The intervention component was designed to enhance parents' perception of control and to increase problem solving, emotion-regulation, and coping skills. Parents were taught diaphragmatic breathing, PMR, and imaginal distraction, and were given audiocassettes guiding them on how to prepare their child for surgery. Parents were also given a homework booklet which outlined a way to practice the learned techniques and also to record the techniques which were practiced; home practice prior to hospitalization was encouraged via phone calls from the experimenter. Using self-report and observational measures, differences were found between groups in both parents and children. Children in the treatment group were described as more cooperative and less upset while in the hospital, better adjusted at home after discharge, and higher functioning in school. Parents in the treatment group reported greater confidence in their ability to care for their child both in the hospital and following discharge. The study by Campbell et al. (1995) improves upon past research in terms of increased methodological rigor, and applicability to chronically ill children undergoing more extensive medical procedures.

Several studies have focused specifically on stress and anxiety reduction in children with cancer (Jay, Elliott, Katz, & Siegel, 1987; Jay, Elliott, Woody, & Siegel, 1991), yet fewer have included parents in preparations for such children's medical procedures or surgery. Jay and Elliott (1990) developed a stress inoculation program to

ameliorate parents' stress associated with their child's bone marrow aspiration (BMA) and lumbar puncture (LP) procedures. All children were part of a larger study examining the role of coping skills training in conjunction with medication. Seventy two parents were assigned to either the parent intervention stress inoculation or the child-focused group. Parents in the child-focused group were present during their child's procedure, yet were not given instructions as to how to reduce their anxiety or stress. Parents in the stress inoculation group received one 45 minute session on the morning of the procedure. Components of the intervention included filmed modeling and education, self-statement training, and relaxation training with coping imagery. A videotape demonstrating a parent coping with his/her child's medical procedure was used, and parents were given an audiocassette with the relaxation training for future use. Self-report, observational, and physiological measures were used.

Findings from Jay and Elliott (1990) indicated parents in the stress inoculation group had lower levels of both state and trait anxiety. However, differences between the groups were found only on self-report measures. Parents reported relaxation training as the most helpful of the various intervention components. The authors suggested lengthening the intervention to allow further discussion and practice of the three components. Jay and Elliott's preparation program was unique in that it focused on reducing parents' own anxiety and stress about the procedure, rather than assistance in helping the child to cope with the procedure.

Overall, findings from the intervention literature indicate that preparations are indeed helpful. Levels of anxiety in both parents and children, as well as uncooperative

behavior in children, have been found to be lower in groups of parents and children who have undergone preparation programs (Campbell et al., 1986, 1995; Jay & Elliott, 1990; Wolfer & Visintainer, 1979; Zastowny et al., 1986). Findings demonstrate the utility of receiving information with the incorporation of cognitive behavioral techniques. Specifically, PMR and coping self-statements have been found to be effective (Campbell et al., 1986, 1995; Jay & Elliott, 1990; Singer et al., 1988; Zastowny et al., 1986).

Varying levels of intensity of interventions have also been explored, with effectiveness seen in one-session (Jay & Elliott, 1990) through eight-session (Singer et al., 1988) preparations. Furthermore, the use of homework assignments (Singer et al., 1988), or written material about intervention strategies (Wolfer & Visintainer, 1979), has also been shown to be effective. Self-report and observational measures have been used most frequently in assessing change, and the importance of the use of standardized measures has been widely demonstrated (Robinson & Kobayashi, 1991; Wolfer & Visintainer, 1979).

<u>Medical Aspects of Bone Marrow Transplantation</u>

Individuals whose diseases are unlikely to be cured by other treatments and who have a suitable source of bone marrow available to them are candidates for BMT (McConville et al., 1990). There has been much success reported in using BMTs to treat acute leukemias. Other cancerous disorders for which BMTs have recently been utilized are chronic leukemias, lymphomas, neuroblastomas, and tumors sensitive to radiation (Lesko, 1989; Wiley & House, 1988). BMTs have also proven successful for treating individuals with noncancerous disorders such as genetic disorders of bone marrow,

thalassemia, severe aplastic anemia, and some congenital hematological disorders. Although the proposed study encompasses the use of BMTs for both cancerous and noncancerous disorders, its focus is primarily on children with cancerous illnesses.

In BMT, the patient's own bone marrow is destroyed through high levels of medications before the patient is "transplanted" with either his/her own treated marrow or marrow from a matched related or unrelated donor. Three types of BMTs are currently performed. Autologous transplants occur when the patient's normal appearing bone marrow is extracted, often treated with cytotoxic drugs or antibodies directed toward cancer cells, and cryopreserved (Pinkel, 1993). Allogeneic transplantation involves transplanting marrow from another person into the patient, therefore necessitating extensive medical evaluations of potential donors. The donor of the marrow may be a relative who has been determined to have several human leukocyte antigens (HLAs) which match the patient, or a non-relative donor usually located through the use of the Bone Marrow Transplant Registry may also be used. The third type of BMT is syngeneic transplants. These occur when the donor is an identical twin who therefore has an identical HLA match with the patient.

The BMT process can be thought of as occurring in stages (Brown & Kelly, 1976) beginning with one's decision to pursue BMT as a treatment and ending with adaptation following discharge from the hospital. Although BMT has previously been used primarily as a last attempt to remove disease, patients with cancerous illnesses are increasingly undergoing BMT at earlier phases of their illness. As such, many patients are undergoing BMT during their first remission. Many times, patients first learn of BMT

as a treatment option early on in the treatment process. As BMT is not widely offered, patients are typically referred to a tertiary care center which may not be in close proximity to the patient's home. Prior to admission to the BMTU, patients typically undergo physical evaluations and, depending on the transplant center, may also undergo an evaluation from psychology and/or social work services. As successful BMT calls upon multiple family resources (e.g., finances, social support), many professionals, as well as all available family members, are included in the evaluation process.

The portion of the BMT process which occurs in the hospital begins with the child's admission to an isolated, sterile room where he/she will remain until discharge. Laminar airflow units are used, as are reverse-isolation rooms. Precautions taken prior to entering patients' rooms vary with transplant centers and may include washing hands, wearing a mask, wearing a gown, and disinfecting any objects to be brought into the room. Upon admission, a central venous catheter is implanted while the patient in under general anesthesia. This central line facilitates drawing of blood, injection of medications, and transfusion of total parenteral nutrition (TPN), while minimizing the times the patient's skin is punctured and decreasing their susceptibility to infection as well as their experience of pain. Through the patient's central line, high levels of chemotherapeutic agents are transfused. For approximately 7-10 days between admission and transplant, the patient's immune system is challenged with lethal doses of these agents in an effort for the patient to become as disease free as possible prior to transplant. In addition to the chemotherapeutic agents, some patients undergo total body irradiation (TBI). This period of time, often referred to as the 'conditioning phase', results in

increased levels of patient discomfort and may be marked by nausea, vomiting, fatigue, and lowering blood counts.

The transplant itself is typically uncomplicated and involves infusion of the donated or treated marrow through the central line. When a relative is the donor, he/she may donate the marrow at an earlier date or may be brought into the hospital on the day that the new marrow is to be transplanted. Few side effects, aside from minor soreness around extraction sites, are generally associated with bone marrow donation.

The period of time immediately following transplantation can be characterized as a time of waiting; it typically takes from 10 to 20 days before the donor cells in the marrow mature and engraft in the patient's body (Hutchison & Itoh, 1982). Patients and their families anticipate results of frequent laboratory tests to determine if engraftment of the marrow has begun, indicating preliminary success of the transplant. During this time, patients continue TPN and antibiotic coverage. Side effects from the chemotherapeutic agents often remain, with mucositis or mouth sores a frequently cited source of discomfort for the patient. During this time, some children are given patient-controlled analgesia to assist in pain management (Dunbar et al., 1995).

Graft versus host disease (GVHD) is a possible side effect or outcome of BMT, and may surface during the stage of engraftment or as late as after discharge. GVHD is characterized by diarrhea, skin rash, gastroenteritis, and hepatic dysfunction (Pinkel, 1993). GVHD occurs when competent engrafted cells recognize the patient's antigens as foreign and react against them; the patient's immune system is compromised and therefore unable to reject the attacking engrafted cells. Fifty percent of all patients

develop some form of mild to moderate GVHD (Dunbar et al., 1995; Lesko,1989), while others go on to develop chronic GVHD approximately 3-6 months posttransplant (Pinkel, 1993). Although GVHD can result in encephalopathy (Mott et al., 1995) or even be fatal in some instances, it is typically treatable with medication.

As engraftment occurs, patients continue to receive antibiotics and must remain in a germ-free environment. Though eating foods is permitted, patients often continue to be fed through hyperalimentation (TPN) in order to receive their necessary nutrients. Liquids and small meals which are considered safe (little chance for contamination by bacteria) are encouraged, though many patients are unable to eat without becoming nauseous and therefore remain on TPN even after discharge; one side effect of TPN is temporary loss of the basic functions associated with eating.

Once blood counts have stabilized, patients and their families may begin to prepare for discharge. Many centers require caregivers to have demonstrated their ability to care for the patient at home (i.e., change central line dressing) prior to discharge. Once discharge occurs, centers often require patients to remain close by increasing ease of accessibility to the clinic. Patients are typically instructed to visit the outpatient clinic several times weekly for the first several months post-transplant. At home, patients must be carefully monitored, and readmission to the transplant center may be necessary. Pronounced immunologic impairment lasts up to four months following BMT, and the patient's immune system is not considered to be functioning at a normal healthy level until up to 12-18 months post-BMT (Hutchison & Itoh, 1982). Therefore, contact with

potentially infectious agents, such as large groups of people, animals, and plants, must continue to be minimized.

Though most studies involving BMT have focused on factors predicting success, some attention has been paid to long-term sequelae for children undergoing BMT. In his review article on BMT in children, Pinkel (1993) cites growth failure, chronic GVHD, multiple endocrine disorders, second cancers, sterility, renal insufficiency, and cardiomyopathy among his list of possible long-term consequences for children undergoing this treatment. It should be noted that controlled studies of contributing factors to such sequelae have not yet been reported.

Recent advances in BMT include stem-cell replacement and cord blood transplants. Though relatively new, cord blood transplants utilizing stem cells from umbilical cords have been successfully performed on children in several countries (Gluckman, 1994; Gluckman et al., 1992). Transplants from cord blood are thought to be associated with a lower risk of GVHD. Furthermore, cord blood transplants are considered advantageous given that they do not require a donor to undergo an otherwise unnecessary surgical procedure. As a result, cord blood banks are increasing in number, and transplants using cord blood are beginning to be used in adults (Gluckman, 1994; Gluckman et al., 1992).

<u>Psychological Aspects of Bone Marrow Transplantation</u>

In addition to the aforementioned physical complications related to BMT, the demands placed upon the patient and his/her family may also lead to psychological complications. Even before the child is admitted to the BMTU, various stressors may be

in place. For example, adjusting to the diagnosis, preparing for relocation to the medical

center, waiting for a matched donor, organizing finances, arranging child care for other

children in the family, and preparing for the possibility of death are just a small sample of

issues for families at this time (Hare, Skinner, & Kliewer, 1989; Rodrigue, Greene, &

Boggs, 1994). In addition, a family may bring marital tension or pre-illness psychological

symptomatology into the transplantation process.

A child's ability to cope with the BMT process is thought to depend on the child's

age, developmental stage, cognitive level, individual personality, and supportive network.

The family is considered to be a child's greatest source of support (Wiley & House,

1988). When support is inadequate, or other demands do not allow the child to adjust and

adapt to BMT, symptoms may include depression, anxiety, fear, anger, belligerence,

regression, mood fluctuations, and anorexia (Lesko,1989; Gardner, 1977; Rodrigue et al.,

1994; Wiley & House, 1988).

Through the entire transplantation process, the child, his/her siblings, parents, and

also the bone marrow donor are coping with a great number of stressors. At the time of

admission, children and their parents must contend with the isolation of the child. Such

strict regulations regarding a germ-free environment can promote feelings of barriers to

communication and closeness between parents and child (Brown & Kelly, 1976). In

addition, near the time of admission, parents and children may second guess their

decision to pursue BMT.

The conditioning phase, during which time the child is given lethal amounts of

chemotherapeutic agents, may also be associated with alterations in psychological

functioning. Aside from the various changes in behavior or attitude that may result from the child's frustration with feeling ill, psychiatric symptoms or lability of affect may be caused by the large doses of medications (Brown & Kelly, 1976; Lesko, 1989). Though the actual event of the marrow being transplanted is thought to be generally non-aversive in allogeneic transplants, concerns regarding the donor's health status and well-being may be expressed by either the recipient or the family. Although the risk is minimal, parents may feel guilty about subjecting a healthy child donating the marrow to general anesthesia. Similarly, donor siblings may feel responsible for the outcome of transplantation. Furthermore, non-donor siblings may feel rejected, useless (Freund & Siegel, 1986; Lenarsky & Feig, 1983), or otherwise disenfranchized from the treatment process.

Following transplantation is a time marked by waiting for laboratory results to indicate signs of engraftment. While the child may be in great discomfort and pain from chemotherapeutic side effects and continued antibiotics, parents must still encourage children to cooperate with, and actively participate in, their treatment regimen (Wiley & House, 1988). This may be particularly difficult for parents. After engraftment, children and families may feel successful, yet they must also recognize the remaining risks. Therefore, necessary precautions must be followed after discharge.

Preparing for discharge brings additional stressors to the child and his/her family. Because of the safety often felt while a child is monitored by the medical staff 24 hours a day, many families feel incompetent or inadequate in caring for the child's needs out of the hospital environment (Freund & Siegel, 1986; McConville et al., 1990). Children

may become more dependent on parents and also more demanding once leaving the hospital environment. In a descriptive study of seven parents of children who had recently undergone BMT, White (1994) found parents to have multiple concerns regarding discharge including changing relationships and uncertainty of the future. More specifically, parents reported themselves as being concerned about changes in the marital relationship, and relationships among siblings. Furthermore, parents continued to worry about future relapses or long-term side effects from the BMT and associated treatments.

Other research examining the psychosocial sequelae of children undergoing BMT has been largely retrospective in nature. However, findings have revealed a number of psychosocial variables to be associated with the transplantation process. Overall, studies have found children to be generally stressed, exhibit poor adherence, have low social competence and self esteem, and have multiple concerns upon discharge. In an early study involving children undergoing BMT, Gardner et al. (1977) used both projective and objective measurements to conclude that children usually had problems in five different areas. These areas included (1) anxiety and depression secondary to invasive medical procedures and fear of dying, (2) overly dependent behavior and associated feelings of helplessness, (3) anger toward parents and staff, (4) diminished tolerance for medical procedures, and (5) episodic refusal to cooperate with treatment demands. Gardner and her colleagues cite the importance of honest communication between the child and parents or hospital staff, in terms of discussing all aspects of transplantation, including the possibility of various complications and even death.

Stuber et al. (1991) examined post-traumatic stress disorder (PTSD) symptomatology in six children who underwent BMT. Children were examined through the use of both a structured interview and an observational projective measure of the child's play. Assessments occurred pre-transplant and again three, six, and 12 months post-transplant and indicated increases in PTSD symptomatology at three months post transplant, with slight declines at 6 and 12 months. The authors suggested the benefit of using PTSD as a model in understanding some of the symptoms that children BMT recipients report.

Lee, Cohen, Stuber, and Nader (1994) examined the relationship between parent-child interactions and children's PTSD symptomatology. Parents of children undergoing BMT who had lower rates of responsiveness in their interactions with their children had children who reported fewer PTSD symptoms. Furthermore, parents who utilized social support and focused on the positive aspects of events also had children who reported fewer symptoms of PTSD. This investigation used the same six children as the Stuber et al. (1991) study, and findings are therefore limited given the small sample size.

The relationship between PTSD symptomatology and BMT was also discussed in a review of the literature by Heiney, Neuberg, Myers, and Bergman (1994). Combining their clinical experiences with available literature, the authors concluded that parents responses after a child's BMT are often indicative of PTSD symptomatology (e.g., re-experiencing the event, intrusive thoughts). Heiney and her colleagues suggest that interventions based on PTSD framework be designed to help these parents.

In another review of the literature, Freund and Siegel (1986) also cited difficult times for families including both the sibling and marital relationships. They suggest several components for intervention with these families: assisting families with discharge, providing a framework for resuming prior activities, sensitizing parents to feelings of the well siblings, assisting parents in accepting changes in their relationship, and community outreach. Artinian's (1984) work during the early utilization of BMT also called for intervention for children and families. She described the importance of assisting parents in communicating with their children, and specifically highlighted the benefit of discussing the possibility of death.

Sormanti, Dungan, and Rieker (1994) retrospectively examined the psychosocial impact of children following their BMT hospitalization. Information was collected from 73 families in which the child's transplant had occurred at least one year prior. Data were collected via the mail, and all information obtained was through self-report. Overall, parents were not found to be experiencing long-term psychosocial difficulties resulting from their child's transplant. The primary concerns noted by parents included fear of relapse and financial worries.

In a preliminary report of a prospective, longitudinal study examining psychological effects of BMT on children and adolescents, Phipps et al. (1995) described findings using a cohort of 25 children who were assessed pre-BMT and again 6-12 months post transplantation. Measures of intellectual and neuropsychological functioning were also given. Results suggested that compared to pre-transplant scores, children have lower social competence, poorer self concept, and lower feelings of general well-being

post-transplant. However, Phipps et al. relied on children's self-report measures of psychosocial functioning. Furthermore, the measures used were standardized on healthy children, and data from such measures may be misleading when used with a pediatric population.

Utilizing the same participants, Phipps and Mulhern (1995) investigated children's family environment and found it to be a significant determinant of children's adjustment to the transplantation process. Specifically, family conflict reportedly worked as a risk factor, with family cohesion and expressiveness working as protective factors. Phipps and Mulhern's results highlight the individual variability of children and family's responses to the process of BMT.

Utilizing a prospective design, Rodrigue et al. (1996) followed 27 mothers of children undergoing bone marrow, liver, kidney, and heart transplantation. Mothers were assessed pre-transplant, and again at one and six months post-transplantation. Following transplantation, mothers reported having increased parenting stress, financial strain, caregiver burden, and family stress. Such stressors were found to persist for several months post-transplantation. Although only a small number of parents of children undergoing BMT (n=13) were examined, results further support the relationship between BMT and family, or parental stress. The authors suggest the importance of the development of interventions focusing on parents' ability to cope with stress.

Illness severity has also been explored as a possible variable in a child's psychosocial functioning with equivocal findings within the general chronic illness literature. Specific to BMT and through the use of a retrospective design, McConville et

al. (1990) rated children survivors of BMT and non-survivors on measures of psychological distress and medical complications. Their findings indicate increased distress with more severe medical complications.

<div align="center">Summary</div>

Children and their families experience stress in relation to the many aspects of adapting and adjusting to a chronic illness. Findings from the many aforementioned studies that have examined the role of stress in other medical procedures or illnesses, aside from BMT and cancer, can be generalized to include the case of BMT. When compared to parents of other chronically ill children, parents of children undergoing BMT have additional stressors to contend with (e.g., child's isolation, temporary move to tertiary care setting, long-term hospitalization, separation from spouse, uncertainty of child's future). Furthermore, parents of children undergoing BMT have been found to be under much stress (Rodrigue et al., 1996). Therefore, although there are no known empirical studies aimed at decreasing stress in either parents or children undergoing BMT, interventions aimed at managing stress in other populations can provide useful information when considering children and BMT.

SPECIFIC AIMS AND HYPOTHESES

The present study focused on the efficacy of a newly designed intervention aimed at decreasing stress in parents of children undergoing BMT. Type of preparation (intervention or standard care) was the independent variable of interest. Dependent variables included parental stress measured through the use of self-report measures and a semi-structured interview. Parental coping style and major life events, and children's illness severity, were also measured. The specific goals of the study were (1) to provide a means of empirically evaluating the efficacy of the currently used preparation procedure, (2) to help to determine the needs of parents undergoing similar experiences, and (3) to benefit the health care team in assisting patients and their families to cope with the BMT process by decreasing parental stress.

Following were the study's hypotheses:

(1) Parents in the newly designed intervention condition would report lower levels of stress compared to those participants in the standard preparation condition. The finding was expected to be indicated on two self-report measures and also through the use of a semi-structured interview.

(2) Within the intervention group, parents indicating greater use of treatment techniques would report lower levels of stress.

(3) Furthermore, reports of increased levels of stress were expected to be associated with increased illness severity.

METHOD

Participants

Participants were 22 mothers of children ages 2 to 16 years old who underwent BMT at Shands Hospital at the University of Florida. The parent who was expected to be the child's primary caregiver during hospitalization was asked to participate and all participants were mothers. Participation was voluntary and was limited to English speaking parents.

Procedure

Within the psychology service at Shands, families are typically seen for a comprehensive pre-transplant evaluation several weeks prior to the child's BMTU admission. However, given the individual variability in treatment regimens, in addition to families' schedules, families may be seen for their initial evaluation either much earlier or much later than is typically desired (i.e., ranging from several months prior to transplant through the initial day of the child's BMTU hospitalization). Therefore, potential participants were recruited in one of two ways. First, parents who participated in the pre- transplant assessment several weeks prior to their child's admission were given information about the study and asked about their possible interest. For families with a different pre- transplant schedule, parents were recruited via phone or while their child was undergoing treatment as an inpatient. All parents were informed that the purpose of the study was to learn more about the experience of families undergoing a

child's BMT, and to examine different ways of preparing for the treatment and long hospitalization. Parents were told the approximate amount of time that participation required, yet that their time commitment would vary depending on randomly selected assignment. No further information about the purposes of the study or differences in group composition was provided. Participants were enrolled in the study from July, 1996, through November, 1997.

Baseline measures were completed an average of 13 days prior to the child's admission to the BMTU. After completion of baseline measures, participants were randomly assigned to either the intervention or standard preparation group; random assignment was used until one condition was filled with 10 participants, at which time incoming study participants were assigned to the unfilled condition.

During the time period of data collection, 24 children meeting the study's inclusion criteria were admitted to the BMTU. All 24 children's parents were approached, and 22 consented to participate in the study, yielding a 92% rate of participation. Of the two parents who refused to participate, one cited her "dislike of psychologists" and the other was a pregnant mother planning on giving birth about the time of her child's transplant. Of study participants, two parents did not complete questionnaires through the end of data collection. One mother in the Standard care condition chose to discontinue her participation and stated that her participation was "adding to [her] stress instead of assisting [her] through the hospitalization." The other parent with incomplete data was in the Intervention condition; her child died prior to the three week post-transplant assessment time.

During their pre-transplant evaluations, participants in both groups received the standard preparation procedure consisting of meeting with the BMTU pediatric nurse coordinator and social worker, taking a tour of the unit, and viewing an independently produced and distributed videotape designed to address education issues in BMT. Following the pre-transplant baseline assessment, participants in the Intervention group were contacted in order to schedule the intervention session. Considerations in the time frame for scheduling intervention sessions included trying to maximize both adherence to study guidelines and the family's convenience. Intervention sessions were typically held within one week of the child's admission to the BMTU and ranged from one month prior to hospitalization to the day of admission.

Intervention. Participants in the Intervention group were seen by an advanced clinical psychology graduate student for one 90 minute session in the Psychology Clinic at Shands. The intervention followed a stress inoculation model, which has been found to be effective for a variety of stressful situations (Jay & Elliott, 1990; Kendall et al., 1979; Novaco, 1977). Included in the intervention were three main components: (1) *education*: related to children's adjustment, children's reactions to illness and medical procedures, and the relationship between parent and child distress and coping, (2) *relaxation*: progressive muscle relaxation training, deep breathing, and guided imagery--standardized through the use of an audiocassette, and (3) *communication*: related to the child regarding his/her illness, in reference to maintaining family stability while being separated, and in more effectively managing parent-health care team interactions (Atkins & Patenaude, 1987; Miles & Mathes, 1991). Parents in the Intervention group also received a

personalized (e.g., with the child's name) handout illustrating the components of the intervention, with examples of how they could utilize the strategies over the course of the child's hospitalization.

An outline of the preparation program served as a guide to the experimenter during intervention sessions (Singer et al., 1988). To assure the integrity of the intervention, treatment sessions were videotaped. A randomly selected subset of interventions was then examined for content comparison to the treatment outline noted above. Interrater reliability coefficients of the integrity checks were calculated and are presented in the Results section.

Assessment timeline. At baseline, all participants completed the LES, WCQ, DSI, and PSI. The experimenter also administered the demographic questionnaire and semi-structured interview. Mothers' perception of their child's illness severity was assessed by one question at the end of completing each DSI. See Appendix for the timeline of administration of measures.

An experimenter was present during the administration of all measures that were completed during the child's hospital stay in order to help insure their accurate completion; the majority of these administrations took place in the child's hospital room. When children were discharged prior to day +21, data were collected via phone or mail. Completion of most measures took place within the same three hour time span (4 - 7 p.m.) for each participant to further standardize assessments. The rating of BMTU rated illness severity was gathered weekly through individual meetings with unit staff.

<center>Measures</center>

<u>Demographic questionnaire</u>

A demographic questionnaire designed for this study provided the following information: child's and parent's age, ethnicity, household composition, employment and education status, travel distance from home to BMT center, previous hospitalizations and/or BMTs, and type and duration of illness.

<u>Knowledge</u>

Knowledge of information considered important for parents of children undergoing a lengthy hospitalization was assessed through the use of a 12-item multiple choice questionnaire designed for this study. Questions pertained to topics covered during the intervention session. For example, "You can help your child handle the procedures by: (a) telling your child that he/she should not feel any pain, (b) imagining the worst, (c) pretending that everything is going to be OK, or (d) remaining calm and allowing your child to talk about his/her fears." Knowledge was assessed at baseline and again one week prior to transplantation.

<u>Life experiences survey (LES)</u>

To assess life events that occurred during the past year, participants completed the first portion of the LES (Sarason, Johnson, & Siegel, 1978) which focuses on specific events that may be common to a variety of individuals. The LES is a 47-item self-report measure which asks respondents to indicate on a 7-point Likert scale (-3 extremely negative to +3 extremely positive) both whether specific life events/changes have taken place in the past six or 12 months, and the impact that each of these events has had on the

individual. This measure, which asks respondents to indicate the valence of events experienced, was selected because negative life events have been found to be more highly correlated with illness outcome and adjustment than either positive events or combined positive and negative total scores (Johnson, 1986; Sarason et al., 1978). Therefore, in addition to total score, a negative change score, derived from adding the impact ratings of negatively labeled events, was utilized. The LES has been used with a wide variety of populations, and acceptable reliability and validity of the measure has been documented elsewhere (reliability coefficients ranging from .56 to .88; Sarason et al., 1978).

The ways of coping questionnaire (WCQ)

Based on Folkman and Lazarus' (1984) transactional model of stress, the WCQ (Folkman & Lazarus, 1980) measures the types of coping strategies that individuals employ for a specific event appraised as stressful. Respondents indicate how often specific coping behaviors were used (0 = not at all used to 4 = used a great deal). The WCQ has eight subscales: Confrontive, Distancing, Self-Controlling, Seeking Social Support, Accepting Responsibility, Escape-Avoidance, Problem Solving, and Positive Reappraisal. Examination of psychometric properties of the instrument reveals satisfactory reliability and validity estimates (alpha coefficients ranging from .60 to .88; Aldwin, Folkman, Shaefer, Coyne, & Lazarus, 1980; Vitaliano, Russo, Carr, Maiuro, & Becker, 1985). In completing the WCQ, participants were initially asked to keep in mind their child's most stressful previous hospitalization as the specified stressor of reference. At the post-transplant assessment, mothers were asked to consider the child's BMT when completing the measure.

<u>Daily stress inventory (DSI)</u>

Researchers have found stronger relationships between measures of relatively minor stressors and physical and psychological outcomes than with measures of major life events (Bernard & Krupat, 1994; Cohen & Williamson, 1991; Johnson, 1981). The DSI is a 58-item self-report instrument assessing the impact of minor stressful events on a daily basis (Brantley, Waggoner, Jones, & Rappaport, 1987). Respondents are first asked to indicate which of the 58 items occurred in the past 24 hours, and then to rate the degree of stressfulness of each event on a 7-point Likert scale (1 = occurred but was not stressful, 7 = caused me to panic). The number of events endorsed as having occurred, the sum of the total of the impact rating of each of those events, and the average impact rating for all of the events comprise the three daily scores which are derived for each respondent.

Participants were administered the DSI 14 times throughout the study. In order to obtain a more reliable measure of weekly stress, mothers completed the DSI three times per week, on two randomly selected weekdays and one randomly selected day of the weekend. Scores for the three administrations were averaged to yield one DSI score per week. When parents were unavailable to complete the DSI on all three days, an average of data from two data points were used. Through multiple studies, Brantley and his colleagues have demonstrated that the DSI has adequate concurrent and construct validity (correlations with the Hassles scale ranging from .25 to .57) and good reliability (alpha coefficients ranging from .83 to .87; Brantley, Cocke, Jones, & Goreczny, 1988; Brantley & Jones, 1993; Brantley et al, 1987).

Parenting stress index (PSI)

The PSI is a 101-item self-report instrument which was designed to measure the relative magnitude of stress in the parent-child system (Loyd & Abidin, 1985). Responses provide information on three empirically derived factors: child domain, parent domain, and total stress. Due to the inapplicability of several items of the child domain with regard to long-term hospitalization, only the parent domain (items 28-30, 51-101) was administered. The parent domain indicates the degree to which stress is related to parental functioning in seven areas: attachment towards their child, depression, parental sense of competence in the parenting role, relationship with spouse, social isolation scale, parental health, and restrictions of role. The PSI has been used to describe differences in parenting stress across various chronic illnesses (Darke & Goldberg, 1994), and its sensitivity to changes in stress over time has been documented (Goldberg, Morris, Simmons, Fowler, & Levison, 1990; Wells & Schwebel, 1987). Acceptable reliability coefficients (.55 - .93) and validity of the factors have been demonstrated (Abidin, 1995; Loyd & Abidin, 1985).

Semi-structured interview (SSINT)

A semi-structured interview developed for this study assessed the frequency of psychological and physiological symptoms of stress, and the degree to which such symptomatology impacted upon participants' lives. It was intended to provide supplemental clinical data to the research indices of stress. Respondents also indicated how stressed they felt (using a 7-point Likert scale) during specific times in their child's medical care. In addition, symptomatology related to PTSD was examined. At four time

points (baseline [Time 1], Time 2, Time 4, and Time 6), participants responded to SSINT questions about physiological symptoms of general stress and specific stressors of having a child in the hospital for BMT. Interviewers cued participants to consider the previous week in giving their responses. Administration of the SSINT yielded four scores: frequency, change, problem, and specific stress.

Adherence to intervention strategies

Participants also completed a short questionnaire designed for this study that asked which, if any, of the various intervention techniques were used by the participant during the previous week.

Illness severity

Participants rated their perception of their child's illness severity on a 5-point Likert scale (1 = extremely ill, 5 = extremely well). Using the same scale, ratings of illness severity were gathered through individual meetings with attending physicians, physician assistants, and nurses on the BMTU. The child's illness severity rating provided by BMTU staff was determined by averaging ratings gathered for each child.

<div align="center">Analyses</div>

The overall approach for analyzing data followed what is typically used in treatment outcome research. Reliability coefficients for all measures were first calculated. Analyses of variance (ANOVAs) were used to test for significant differences between groups and over time, followed by t tests to further examine significant ANOVA findings. Data were compared to published norms, and then the relationships among the measures were examined. Specific analyses for each hypothesis are listed below.

For hypothesis 1, several analyses of variance (ANOVAs) were conducted on demographic information, self report measures of stress, coping style, and major life events in order to determine differences between groups at baseline. ANOVAs versus MANOVAs were used in order to maximize the amount of useful information that was retained. When appropriate, Welch's t statistics (Nunnally & Bernstein, 1994) were calculated to compare data from this sample with published normative data. Percent change scores were also computed where applicable. Kappa coefficients were calculated to examine reliability of measures at each time point.

For hypothesis 2, bivariate one-tailed correlations between levels of stress and number of intervention techniques used were conducted. For hypothesis (3), the relationship between child's illness severity and parent's report of stress was also explored through the use of bivariate one-tailed correlations. To examine treatment integrity, percentages of content included in intervention sessions were calculated.

RESULTS

Demographics

Background variables were assessed with the demographic questionnaire designed for this study. Comparisons between the two groups (Intervention and Standard Care) were made using independent samples t tests and chi square analyses. No differences were found between groups on any demographic information. Background data for each group are reported in Table 1.

Children ranged in age from two to 16 years with 17 males and 5 females comprising the overall group. The ethnicity of the sample was predominately Caucasian (86%); mothers of two African American children (9%) and one Hispanic child (5%) also participated. Fifty-nine percent of all mothers were married. On average, mothers had a greater than high school education and three mothers (14%) were working outside of the home up until the time of their child's BMT admission. Families who lived closest to the BMT center lived one hour's driving time away, and families living as far as six hours away also participated in the study.

Children's illness characteristics were consistent with those being treated with BMT. Length of diagnosis ranged from two to 139 months and 86% of children had cancerous illnesses, including Ewings Sarcoma (n = 5, 23%), Neuroblastoma (n = 5, 23%), AML (n = 4, 18%), ALL (n = 3, 14%), Osteosarcoma (n = 1, 5%), and Hodgkins (n = 1, 5%). Fourteen percent of children received BMTs for noncancerous disorders

including Schwachman Diamond's Syndrome (n = 1, 5%), Wiskott-Aldrich's syndrome (n = 1, 5%), and Fanconi's Aplastic Anemia (n = 1, 5%). Children in both groups received one of four types of transplants: allogeneic (36%), autologous (27%), cord blood (14%), or stem cell (23%). Donors for allogeneic transplants included one older and one younger sibling, two parents, and four matched non-relatives. The majority of children (81%) had previously been hospitalized at Shands. Number of prior hospitalizations for current illness varied greatly and ranged from one to one hundred (M = 25.8, SD = 28.8, median = 12).

Pretreatment Variables

In order to determine whether the two groups differed on measures of stress at pretreatment, comparisons were made between groups at baseline on all dependent measures. Independent samples t tests were used to examine continuous variables and chi square analyses were used for dichotomous and categorical variables. No significant group differences (all ps > .05) were found on measures of stress (DSI, PSI, SSINT), the Knowledge Questionnaire, Ways of Coping Questionnaire, or Ratings of Illness Severity.

Life Experiences Survey

Table 2 presents the means and standard deviations for the LES. Reliability of the LES was adequate, coefficient alpha = .75. An independent samples t test indicated that parents in the Standard Care group reported significantly fewer positive life events within the last year than did those in the Intervention group, t (18) = -2.41, p < .05. No significant difference was found for the LES negative event score.

As there has been much discussion concerning the most appropriate methods for investigating major life events, data were reanalyzed using a simple frequency count of the total number of events experienced versus an impact score. Using the frequency count method, no differences were found between groups. Therefore, it was decided to not use the LES positive event score as a covariate for further analyses.

<u>Missing Data</u>

Given the repeated measure design of the study, in addition to the intensity of participants' lives during the data collection period, data for several participants are missing at one or more time points. In computing repeated measures analyses with four or more data points, mean substitution (e.g., Intervention group mean for Intervention participants and Standard Care group mean for Standard Care participants) was used. This was considered to be particularly useful given the relatively small sample size; participants' data was not used when one of only two time points for a measure was missing. For two different measures that were given on only two occasions, one participant's data is incomplete, and was therefore not used. Preliminary analyses were conducted both with and without mean substitution, and those utilizing mean substitution are reported.

<u>Hypothesis 1: Examining Differences on Measures of Stress</u>

<u>Daily Stress Inventory: Group and Time Differences</u>

Table 3 provides means and standard deviations for each time point for the DSI Impact Score, as well as an overall average DSI Impact score; coefficient alphas for the DSI at all assessments were excellent ($\geq .94$). Event scores for the DSI are listed in Table

4. One participant's data (in the Intervention group) ranged from greater than three to greater than 25 standard deviations above the mean for that group. This participant was considered to be an outlier for this measure and her data were therefore not used in analyses.

DSI: Impact scores. Differences between the Intervention and Standard Care groups for the six time periods were analyzed by repeated measures ANOVAs. There was a significant main effect for Time, $F(5, 90) = 3.27$, $p = .01$. Post-hoc paired samples t tests were used to examine which time points were most stressful for parents. DSI Impact scores were significantly higher at Time 1 than at Times 4, 5, and 6 ($t(18) = 2.70$, $t(18) = 2.65$, $t(18) = 2.49$, respectively; all ps < .05), with a general trend of decreased stress over time.

To further examine group and time differences, an average DSI Impact score was computed for Times 2 through 6, and was compared with baseline impact scores by a repeated measures ANOVA. There was no significant difference between groups, yet there was a main effect for Time, $F(1, 19) = 5.63$, $p = .028$, indicating the endorsement of greatest impact of stressful experiences at the time point prior to the child's admission.

DSI: Event scores. DSI Event scores were also examined over the six time periods to determine if either group reported themselves as experiencing a significantly greater number of daily stressors, as well as if daily stressors declined over time. A repeated measures ANOVAs showed no significant differences between groups, however, there was a significant main effect for Time, $F(5, 85) = 4.50$, $p = .001$. Paired samples t tests for post-hoc comparisons were used in order to specifically examine ratings of

stressors in relation to the time since the child's admission. Comparisons yielded significant differences between Time 1 and Times 2-5, with more stress at baseline than at any other data point except for Time 6: Time 2, $t(20) = 2.58$, $p = .036$, Time 3, $t(20) = 2.89$, $p = .018$, Time 4, $t(18) = 3.20$, $p = .01$, and Time 5, $t(18) = 3.26$, $p = .008$.

To investigate overall stress as reported by the DSI, an average DSI event score was computed combining data from Times 2 through 6. A repeated measures ANOVA was conducted using two data points per participant: baseline event score and Time 2-6 average event score. No group difference was found; there was a significant main effect for Time, $F(1, 19) = 10.58$, $p = .004$, with participants endorsing the occurrence of more daily stressful events at baseline.

DSI: Comparisons to a normative sample. Comparisons to a normative sample of medical patients were conducted (N = 223, medical conditions included asthma, Crohn's disease, chronic renal failure, angina, and chronic recurrent headaches; Brantley & Jones, 1993). The Welch's t-statistic was selected for conservative comparisons between groups of unequal sample sizes and variances. Compared to the normative sample, Impact scores at Times 4, 5, and 6 were significantly lower for the Total sample (Time 4) and Intervention group (Times 4, 5, and 6), $t(19) = -1.78$, $t(12) = -4.17$, $t(9) = -2.30$, $t(9) = -2.09$, respectively (all $ps < .05$). Event scores for the Total sample at Time 1 were significantly higher than the normative sample, $t(16) = 2.00$, $p < .05$. At Times 4 and 5 the Intervention group had significantly lower Event scores than the normative sample, $t(8) = -2.85$, $t(8) = -2.40$, $ps < .05$.

DSI: Classification of clinical significance. Using the same normative sample of medical patients as described above (Brantley & Jones, 1993), percent change scores were calculated for both DSI Impact and Event Scores (see Table 5). Clinical was defined as greater than or equal to the 85th percentile. For Impact scores, 84% of participants started (Time 1) and ended (Time 6) in the non-clinical range. Within the Intervention group, only one participant's range of score changed, improving from the clinical to non-clinical range (11%). For the Standard Care group, one participant (10%) also improved from the clinical to non-clinical range, and one participant (10%) whose range did not change began (Time 1) and ended (Time 6) within the clinical range.

Percent change scores for DSI Event scores were similar, with 79% of the Total sample beginning (Time 1) and ending (Time 6) within the non-clinical range. In the Intervention group, one participant's score (11%) moved from the non-clinical to clinical range. One participant (10%) in the Standard Care group also moved from a non-clinical to clinical status. The Standard Care group included one participant (10%) improving from a clinical to non-clinical range, and one (10%) remaining the same, beginning and ending within a clinical range.

Semi-Structured Interview: Group and Time Differences

Means and standard deviations for SSINT scores can be found in Tables 6 and 7; coefficient alphas for the SSINT were adequate for frequency scores (all alphas >.80). Repeated measures ANOVAs for frequency, change, and problem scores resulted in no significant main or interaction effects (all ps > .05).

SSINT frequency scores from Times 2, 4, and 6 were averaged to yield one summary frequency variable. A repeated measures ANOVA was conducted using two data points per participant: Time 1 frequency score and the average (for Times 2, 4, and 6) frequency score. No significant main or interaction effects emerged (all ps > .05).

In examining the SSINT's specific stress questions, a repeated measures ANOVA yielded a significant Group x Time interaction, F (3, 60) = 3.36, p = .024, and a main effect for Time, F (3, 60) = 7.83, p = .001. Paired samples t tests were used for marginal and cellwise comparisons. There were no significant group differences at each Time point (all ps > .05). For the Total sample, Time 1 scores were significantly higher than scores at Time 4, t (21) = 2.37, p = .020, and Time 6, t (21) = 4.34, p = .001. Within the Intervention group, specific stress scores at Time 1 were significantly greater than at Time 2, t (10) = 3.68, p = .008, and Time 6, t (10) = 3.69, p = .008. Within the Standard Care group, significant differences were found between Times 1 and 6, t(10) = 2.81, p = .038, with significantly less specific stress reported at Time 6.

Similar to the frequency variable, an average score for Times 2 through 6 was calculated for specific stress. A repeated measures ANOVA using two data points (Time 1 and average Specific stress) resulted in a significant Group x Time interaction, F (1, 20) = 12.13, p = .002, and a significant main effect for Time, F (1, 20) = 5.40, p = .031. For the Total sample, specific stress was rated as higher at Time 1 than at other times combined. Post-hoc independent samples t tests to examine group differences at each time point were not significant (ps > .05). Paired samples t tests indicated that the Intervention group had significantly more specific stress at Time 1 than at all other time

points, averaged together, t (10) = 3.54, p = .005. No time differences were found in the Standard Care group.

At Time 6, the SSINT also incorporated items related to PTSD which summed to one overall PTSD score. No significant group difference was found when analyzing PTSD scores with an independent samples t test.

Parenting Stress Index: Group and Time Differences

Data were unavailable for one participant in the Intervention group at Time 1, and for the two previously mentioned participants who did not complete data collection at Time 6 (one in each of the two groups). Mean substitution was not used given that there were only two administrations of the PSI. Means and standard deviations for the PSI are presented in Tables 8 through 10; higher scores indicate more stress. Coefficient alphas for the measure ranged from .62 to .95.

Separate repeated measures ANOVAs were conducted for the Parent Domain and for each of the seven subscales. No significant effects emerged in examining the Parent Domain or the Isolation, Health, Depression, and Spouse subscales. There was a significant Group x Time interaction effect for the Attachment subscale, F (1, 17) = 8.97, p = .008, and a significant Time effect for Competence and Role Restriction. Results of follow up t tests for the Attachment subscale indicated that Standard Care group participants were more stressed in relation to their attachment to their child prior to the child's hospitalization then after the child was admitted, t (9) = -3.04, p = .028. Time effects indicated the total sample of participants to be experiencing more stress pre-

admission than three weeks after their child's BMT: Competence F (1, 17) = 10.9, p = .004, and Role Restriction F (1, 17) = 4.72, p = .044.

PSI: Comparisons to the normative sample. Participants' scores were compared to the normative sample (non-clinic referred; Abidin, 1995) using the Welch's t-statistic. At Time 1, mothers in the Total sample and Intervention group reported significantly less stress, as indicated by the Parent Domain score, than the normative sample: Total sample, t (14) = -2.10, Intervention group, t (6) = -2.21, ps < .05. Parent Domain scores for these two groups for Time 6 were also significantly lower than the normative sample: Total sample, t (14) = -2.98, Intervention group, t (6) = -3.61, ps < .01.

Regarding PSI subscales, attachment scores were significantly lower at Time 6 for the Total sample, t (14) = -2.30, p < .025, and Standard Care group, t (6) = -2.33, p < .05 as compared to the normative sample. Competence scores at Time 6 for the Total sample, t (14) = -2.27, p < .025 and Intervention group, t (6) = -1.95, p < .05 were significantly lower than those for the normative sample. For the Depression score, all three groups had significantly lower scores than the normative sample: Total sample, t (14) = -4.36, p < .001, Intervention group, t (6) = -3.03, p < .01, and Standard Care group, t (6) = -3.02, p < .025. A significant difference in parental Isolation at Time 6 was found between the Intervention group and normative sample, t (6) = 3.64, p < .005, with lower stress scores reported by parents in the Intervention group. Role Restriction scores were also significantly lower in this sample as compared to the normative sample: Total sample, t (14) = -3.74, p < .005, Intervention group, t (6) = -3.59, p < .005.

PSI: Classification of clinical significance. Using the normative sample (Abidin, 1995), percent change scores were calculated for the PSI Parent Domain and each of the 7 subscales (see Tables 11 through 13). Clinical was defined as greater than or equal to the 85th percentile. Nineteen participants had complete data and were used in this analysis. For the Parent Domain, 95% of participants started (Time 1) and ended (Time 6) in the non-clinical range. One participant's score (who was in the Standard Care group) also remained unchanged, although she began and ended in the clinical range.

For Attachment scores, 84% of participants in the Total sample began and ended in the non-clinical ranges. One participant's score worsened to a clinical range at Time 6 (Intervention group), and one participant from each group had scores that improved from clinical to non-clinical ranges at Time 6. Results for the Depression subscale were similar: 84% of participants in the Total sample were unchanged (non-clinical to non-clinical), one participant in the Intervention group went from a non-clinical to clinical score, and one participant from each group went from clinical to non-clinical scores.

Within the Competence subscale, 84% of participants in the Total sample remained in the non-clinical range at Time 6. One participant from the Standard Care group went from a non-clinical to clinical score, while one participant from each group improved from clinical to non-clinical. The Spouse subscale demonstrated the most variability with 68% of the Total sample having non-clinical scores at both time points. Sixteen percent of the Total sample's scores also remained unchanged, yet were in the clinical ranges at both time points (two Standard Care participants and one Intervention participant). Within the Isolation subscale, 79% of the Total sample began and ended in

the non-clinical range. One participant in the Standard Care group had clinical scores at both time points, one participant also in the Standard Care group had a non-clinical score at Time 1 and a clinical score at Time 6, and two participants improved to non-clinical scores at Time 6 (one from each group). For Health scores, 84% of the Total sample had non-clinical scores at both times, 10% (one participant from each group) of the sample had clinical scores at both time points, and one Standard Care participant's score improved from clinical to non-clinical. Role Restriction scores indicated that 84% of the Total sample remained in the non-clinical range at Time 6, one Standard Care group participant had clinical scores at both times, and two participants in the Standard Care group had scores moving from clinical to non-clinical.

<u>Ways of Coping Questionnaire: Group and Time Differences</u>

Although the WCQ was not a dependent measure for Hypothesis 1, it was hypothesized that more positive coping strategies would be used by mothers in the Intervention group posttreatment. Tables 14 through 16 provide descriptive data; coefficient alphas ranged from .33 to .86 for the subscales and were .76 and .94 for the overall measure at Times 1 and 6, respectively. Two participants' data in the Intervention group were unavailable for Time 1, and one participant from each of the groups did not complete measures at Time 6. No mean substitution was used given that the WCQ was administered at only two time points.

Repeated measures ANOVAs showed no significant main or interaction effects for the following subscales: Distancing, Self- Controlling, Social Support, Accepting

Responsibility, and Problem Solving. Results for other subscales revealed one significant interaction and two significant main effects for Time.

Within the Positive Reappraisal subscale, there was a significant Group x Time interaction effect, $F (1, 16) = 8.3$, $p = .01$. To further examine use of Positive Reappraisal, and to specifically determine whether parents in the Intervention group used more of this coping strategy at Time 6 than pre-admission, follow up t tests were computed. Results indicated that mothers in the Intervention group had higher Positive Reappraisal scores at Time 6 than did mothers in the Standard Care group, $t (18) = -2.46$, $p = .048$. On the Confrontive subscale, scores for the Total sample were significantly greater at Time 1 than at Time 6, $F (1, 16) = 13.56$, $p = .002$. For the Escape Avoidance subscale, parents in both groups used more Escape-Avoidance coping strategies 3 weeks post-transplant than they did prior to their child's BMTU admission: $F (1, 16) = 9.57$, $p = .007$.

WCQ: Composite scores for positive and negative coping strategies. To more closely compare the use of coping strategies considered to be positive from those considered to be more negative, subscales were combined to yield two scores: Overall Positive coping (Confrontive, Self-Controlling, Seeks Social Support, Accepting Responsibility, Problem Solving, and Positive Reappraisal) and Overall Negative coping (Distancing and Escape- Avoidance). Means and standard deviations for these composite scores can be found in Table 17. A repeated measures ANOVA revealed no significant main or interaction effects for the Positive Coping score. For the Negative Coping composite score, no group differences emerged, however, participants generally

reported using fewer Negative coping strategies after their child's transplant than they did pre-admission: $F (1, 16) = 8.08$, $p = .012$.

<u>Hypothesis 2: Relationship Between Intervention Techniques and Measures of Stress</u>

<u>Intervention Techniques: Group and Time Effects</u>

Means and standard deviations for the Strategies checklist are reported in Table 18. Overall, participants in the Intervention group endorsed using an average of 3 more strategies per week than individuals in the Standard Care group. Given that an increased use of strategies was hypothesized to be associated with less reported stress, and that the first hypothesis examined group differences in reported stress, group differences in reported use of strategies were first examined. A repeated measures ANOVA resulted in a significant main effect for Group, $F (1, 18) = 5.78$, $p = .027$, with participants in the Intervention group reporting the use of more strategies than participants in the Standard Care group.

<u>Relationship Between Strategy Use and Outcome Measures</u>

The relationship between strategy use and stress was examined using the average strategy score and average DSI and SSINT scores, WCQ scores from Time 6, and PSI scores from Time 6. Data were not examined by separate Time points in order to limit the number of correlations (n = 23). Correlations between Strategy use and DSI and SSINT scores are reported in Table 19, between Strategy use and PSI scores in Table 20, and between Strategy scores and WCQ subscales in Table 21. Correlations were examined using both corrected (alpha/number of correlations) and non-corrected p values. Using corrected p values, no correlations were statistically significant across all measures.

Using a non-corrected p value, no statistically significant findings emerged for the DSI, SSINT, and PSI, yet several trends were noted. Also using non-corrected values, four subscales of the WCQ as well as the Positive coping composite score were significantly correlated with the average Strategy score (r's ranged from .45 to .53, all ps $\leq$ .025).

Knowledge Questionnaire

Means and standard deviations for the Knowledge Questionnaire, in addition to its correlation with the average Strategy score, can be found in Table 22; coefficient alphas for the measure were poor (alphas = .37 and .56). A repeated measures ANOVA was computed and resulted in no significant Group or interaction effects, although a significant Time effect was found, $F (1, 19) = 5.20$, $p = .034$. Participants in general were found to have increased levels of knowledge post-admission versus at baseline. To assess the relationship between knowledge and use of intervention techniques, one-tailed bivariate correlations were computed and no statistically significant findings emerged.

Hypothesis 3: Relationship Between Reported Illness Severity and Measures of Stress

Illness Severity

Means and standard deviations for Illness Severity are reported in Table 23; mean substitution was not used for either Illness Severity measure. To examine similarities between parents' and medical staffs' perceptions of children's illness severity, a correlation between the average score for each was computed; parents and BMTU staffs' ratings were not significantly related to one another ($r = .30$, $p > .05$).

Reports of poorer illness severity, as indicated by both participant and BMTU staff, were hypothesized to be related to increased levels of stress. Differences between

groups and across time were examined through separate repeated measures ANOVAs with six Time points for parents' rating of illness severity and five Time points for ratings from BMTU staff. No group differences were found in either analysis.

For parents' rating of illness severity, there was a significant main effect for Time, $F(5, 75) = 4.56$, $p = .001$. Post-hoc paired samples t tests were computed and indicated that parents perceived their child to be in better health at Time 1 than at either Time 2, $t(20) = 2.51$, $p = .021$, Time 3, $t(19) = 2.26$, $p = .036$, or Time 4, $t(17) = 3.17$, $p = .006$. Participants endorsed poorer health for their child at Time 4 versus Time 5, $t(18) = -2.14$, $p = .046$. At 3 weeks post-transplant, however, parents perceived their children to be in better health than at transplant, or at 1 and 2 weeks post-transplant ($t(19) = -3.05$, $p = .007$, $t(18) = -3.74$, $p = .002$, $t(18) = -5.24$, $p = .001$, $t(18) = -3.44$, $p = .003$, respectively). An independent samples t test was conducted to examine group differences on average scores of illness severity for both parent and BMTU staff report; no significant differences were found.

Disease Length

The relationship between children's disease length, as measured by parent report, and outcome measures of stress was examined. Two-tailed bivariate correlations were computed given that there were no specific hypotheses for direction of the relationship. Correlations are reported in Tables 19, 20, and 21; no significant correlations were found.

Treatment Integrity

Two raters coded five (45%) randomly selected videotaped interventions in order to assess treatment integrity. Raters compared videotaped interventions to an outline

listing 27 main points that were meant to be covered during the intervention session. Raters coded the main point in one of two ways: "was said" or "was not said". Overall treatment integrity was very high. Only three points as rated by one rater over two different intervention sessions were coded as "not said". Results from Rater 1 yielded 100% treatment integrity, and Rater 2's treatment integrity was scored as 97.8 %.

<div align="center">Coinciding Psychological Treatment</div>

Seven children and families of participants, including participants themselves, were provided psychological services by a graduate student or intern from Clinical and Health Psychology during the time of this study. The therapist of each of these seven families was given a Strategies Checklist after the three week post-transplant data collection point, and was asked to indicate which, if any, of the 14 Strategies items he/she specifically taught the participant during the course of treatment. This was done to examine differences between groups, and to attempt to assess confounds of the Standard Care and Intervention group assignment. All seven therapists completed the checklist. Four families who were followed by the Psychology service were in the Standard Care group and three were in the Intervention group; treatment ranged from beginning pre-admission to after transplant, and number of sessions ranged as well. Number of strategies taught by the therapist ranged from one to five ($M = 3.0$, $SD = 1.8$) for the Total sample, with $M = 2.7$ ($SD = 2.5$), and $M = 3.3$ ($SD = 1.5$) for the Intervention and Standard Care groups, respectively.

Table 1   62

Background Data

Child Characteristics	Total Sample (N=22)	Intervention (n=11)	Standard Care (n=11)
Age (years; M ± SD)	8.7 ± 4.8	9.4 ± 4.5	8.0 ± 5.2
Sex			
Male	17 (77)	8 (73)	9 (82)
Female	5 (23)	3 (27)	2 (18)
Grade in School (M ± SD)	4.0 ± 3.8	4.5 ± 3.5	3.5 ± 4.2
Ethnicity			
Caucasian	19 (86)	9 (82)	9 (82)
African American or Hispanic	3 (14)	2 (18)	2 (18)
Illness Characteristics			
Cancerous? (yes)	19 (86)	9 (82)	10 (91)
Length of Diagnosis (months; M ± SD)	23.2 ± 32.2	30.0 ± 41.4	16.4 ± 19.2
Type of Transplant			
Allogeneic	8 (36)	5 (45)	3 (27)
Autologous	6 (27)	2 (18)	4 (36)
Cord Blood	3 (14)	1 (9)	2 (18)
Stem Cell	5 (23)	3 (27)	2 (18)
Previous Hospitalization at Shands? (Yes)	18 (82)	10 (91)	8 (73)
Previous Hospitalizations[a]	25.6 ± 28.8	33.4 ± 35.2	18.2 ± 19.4
Parent Characteristics			
Age (years; M ± SD)	36.8 ± 6.9	37.2 ± 5.2	36.5 ± 8.5
Education (years; M ± SD)	13.0 ± 2.8	13.1 ± 3.1	12.9 ± 2.7
Marital Status			
Married	13 (59)	6 (55)	7 (64)
Single[b]	9 (41)	5 (45)	4 (36)
Driving Time From Home to Shands (hours; M ± SD)	2.7 ± 1.4	3.1 ± 1.8	2.4 ± .83

Note. Data are n (%) unless otherwise stated. [a]Number of hospitalizations ranged from 1-100, median number of hospitalizations was 12.0. [b]Includes data from parents who were never married, separated, divorced, or widowed.

Table 2

63

Means and Standard Deviations for the Life Experiences Survey

	Total Sample (N=22)	Intervention (n=11)	Standard Care (n=11)
Number of Total Events in Last Year	8.5 ± 4.4	8.8 ± 3.7	8.3 ± 5.0
[Coefficient alpha]	[.75]		
Total Positive Impact of Events in Last Year	6.8 ± 5.1	9.6 ± 6.1^a	4.6 ± 3.2^a
Total Negative Impact of Events in Last Year	-9.0 ± 7.5	-6.6 ± 5.8	-10.6 ± 8.7

Note. Possible scores range from 0 - 60 for total events, 0 - 180 for positive impact, and -180 - 0 for negative impact. Means with identical superscripts are significantly different from one another at $p < .05$.

Table 3 64

Means and Standard Deviations for the Daily Stress Inventory: Impact Score

	Impact		
	Total Sample	Intervention	Standard Care
Time 1 (Baseline)	30.7 ± 29.4[a,b,c]	26.0 ± 20.2	34.9 ± 36.3
%ile rank	77th	72nd	81st
n	21	10	11
Time 2 (Day -7)	27.4 ± 35.0	22.3 ± 21.7	32.0 ± 44.5
%ile rank	73rd	65th	79th
n	21	10	11
Time 3 (Day 0)	21.2 ± 23.3	16.8 ± 16.8	25.3 ± 28.1
%ile rank	64th	56th	72nd
n	21	10	11
Time 4 (Day +7)	14.0 ± 14.3[a,*]	8.7 ± 7.5[*]	18.8 ± 17.5
%ile rank	52nd	34th	59th
n	19	9	10
Time 5 (Day +14)	15.3 ± 14.4[b]	12.8 ± 9.2[*]	17.6 ± 18.1
%ile rank	53rd	47th	57th
n	19	9	10
Time 6 (Day +21)	16.1 ± 13.2[c]	13.2 ± 9.6[*]	18.6 ± 15.9
%ile rank	54th	48th	56th
n	19	9	10
Average DSI	22.0 ± 20.2	20.1 ± 18.0	23.9 ± 22.8
%ile rank	65th	62nd	70th
n	21	10	11
Normative Sample[d]	20.2 ± 21.0, N = 223		

Note. Possible scores range from 0 - 406 with higher scores indicating greater perceived daily stress. Data do not include the participant considered to be an outlier. Using mean substitution, one additional participant's data were able to be utilized in each of the two groups. Means with identical letter superscripts are significantly different from one another at p < .05 and represent general trends of decreased stress over time. [d] Medical patients (Brantley & Jones, 1989). [*] Significantly different from normative sample (p<.05).

Table 4   65

Means and Standard Deviations for the Daily Stress Inventory: Event Score

	Event		
	Total Sample	Intervention	Standard Care
Time 1 (Baseline)	$12.0 \pm 7.7^{a,b,c,d*}$	11.1 ± 6.1	12.8 ± 9.2
%ile rank	75th	72nd	77th
n	21	10	11
[Coefficient alpha]	[.94]		
Time 2 (Day -7)	7.7 ± 5.6^{a}	7.7 ± 4.5	7.7 ± 6.6
%ile rank	52nd	52nd	52nd
n	21	10	11
[Coefficient alpha]	[.96]		
Time 3 (Day 0)	8.2 ± 7.2^{b}	5.9 ± 4.6	10.2 ± 8.7
%ile rank	55th	43rd	67th
n	21	10	11
[Coefficient alpha]	[.96]		
Time 4 (Day +7)	6.7 ± 6.1^{c}	$4.7 \pm 4.5^{*}$	8.9 ± 6.9
%ile rank	47th	37th	59th
n	19	9	10
[Coefficient alpha]	[.98]		
Time 5 (Day +14)	7.0 ± 5.3^{d}	$5.4 \pm 4.1^{*}$	8.3 ± 5.9
%ile rank	48th	40th	55th
n	19	9	10
[Coefficient alpha]	[.98]		
Time 6 (Day +21)	8.1 ± 6.2	6.4 ± 4.1	9.4 ± 6.3
%ile rank	54th	45th	62nd
n	19	9	10
[Coefficient alpha]	[.98]		
Average DSI	7.7 ± 5.4	6.5 ± 3.9	8.8 ± 6.5
%ile rank	52nd	46th	58th
n	21	10	11

Normative Sample[e] $8.5 \pm 7.1, N = 223$

Note. Possible scores range from 0 - 58 with higher scores indicating a greater number stressful events. Data do not include the participant considered to be an outlier. Using mean substitution, one additional participants' data were able to be utilized in each of the two groups. Means with identical letter superscripts are significantly different from one another at $p < .05$ and represent general trends of decreased stress over time. [e]Medical patients (Brantley & Jones, 1989).
*Significantly different from normative sample ($p<.05$).

Table 5

DSI Percent Change Scores

Group	Subject Number	DSI Impact[a]				DSI Event[b]			
		Non-non (same)	Clin-clin (same)	Non-clin (worse)	Clin-non (better)	Non-non (same)	Clin-clin (same)	Non-clin (worse)	Clin-non (better)
Intervention (n=9)*		8 (89)	0 (0)	0 (0)	1 (11)	8 (89)	0 (0)	1 (11)	0 (0)
	100	X				X			
	101	X				X			
	105	X				X			
	111	X				X			
	115				X			X	
	118	X				X			
	120	X				X			
	121	X				X			
	122	X				X			
Standard Care (n=10)*		8 (80)	1 (10)	0 (0)	1 (10)	7 (70)	1 (10)	1 (10)	1 (10)
	102	X				X			
	103	X				X			
	104	X				X			
	106	X						X	
	107	X				X			
	108				X				X
	109	X				X			
	113	X				X			
	116		X				X		
	119	X				X			

Note. *Data are n (%) based on number of subjects within each group. One death and one outlier occurred in the Intervention group. One dropout occurred in the Standard Care group. DSI medical patient norms (Brantley & Jones, 1989): T ≥ 61, ≥ 85th %ile. [a]M=20.2, SD=21.0, cutoff ≥ 42; [b]M=8.5, SD=7.1, cutoff ≥ 16

Table 6 67

Means and Standard Deviations for the SSINT: Frequency and Change Scores

	Frequency			Change		
	Total Sample	Intervention	Standard Care	Total Sample	Intervention	Standard Care
Time 1 (Baseline)	8.1 ± 6.4	6.6 ± 6.1	9.5 ± 6.8	3.5 ± 3.1	3.1 ± 3.2	3.9 ± 3.1
n	22	11	11	22	11	11
[Coefficient alpha]	[.71]					
Time 2 (Day -7)	6.9 ± 6.1	6.0 ± 7.1	7.8 ± 5.2	2.9 ± 3.0	2.3 ± 3.4	3.5 ± 2.6
n	22	11	11	22	11	11
[Coefficient alpha]	[.81]					
Time 4 (Day +7)	5.6 ± 6.9	4.1 ± 4.6	7.0 ± 7.8	2.3 ± 2.9	1.7 ± 2.3	2.5 ± 3.0
n	20	10	10	20	10	10
[Coefficient alpha]	[.85]					
Time 6 (Day +21)	5.8 ± 5.5	5.8 ± 6.2	5.8 ± 4.4	3.0 ± 3.1	2.6 ± 2.7	3.2 ± 3.1
n	20	10	10	20	10	10
[Coefficient alpha]	[.81]					
Average Score	6.8 ± 3.2	6.4 ± 6.2	7.6 ± 5.2			
n	22	11	11			

Note. Possible scores range from 0 - 51 for frequency scores and 0 - 17 for change scores, with higher scores reflecting more frequent symptoms associated with stress and more change.
Using mean substitution, one additional participant's data were used in each of the two groups.

Table 7

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Means and Standard Deviations for the SSINT: Problem, Specific Stress, and PTSD

	Problem			Specific Stress		
	Total Sample	Intervention	Standard Care	Total Sample	Intervention	Standard Care
Time 1 (Baseline)	2.7 ± 2.8	1.9 ± 2.6	3.6 ± 2.8	$14.2 \pm 6.7^{a,b,c}$	$16.5 \pm 7.5^{d,e,f}$	12.0 ± 5.2^{g}
n	22	11	11	22	11	11
[Coefficient alpha]	[.71]					
Time 2 (Day -7)	2.7 ± 3.0	1.4 ± 2.6	3.6 ± 3.0	10.3 ± 4.6	8.5 ± 4.4^{d}	12.0 ± 4.3
n	22	11	11	22	11	11
[Coefficient alpha]	[.81]					
Time 4 (Day +7)	2.1 ± 2.7	1.4 ± 2.2	2.3 ± 2.8	10.0 ± 5.9^{a}	10.1 ± 7.1	9.9 ± 5.0
n	20	10	10	20	10	10
[Coefficient alpha]	[.85]					
Time 6 (Day +21)	2.1 ± 2.8	1.8 ± 2.4	2.2 ± 2.9	8.4 ± 3.2^{b}	8.3 ± 2.7^{e}	8.5 ± 3.7^{g}
n	20	10	10	20	10	10
[Coefficient alpha]	[.81]					
Average Score				11.0 ± 3.8^{c}	11.3 ± 4.4^{f}	10.7 ± 3.4
n				22	11	11
PTSD	3.3 ± 2.8	2.1 ± 2.7	3.8 ± 2.9			
n	20	10	10			

Note. Possible scores range from 0 - 17 for problem scores, 0 - 49 for specific stress, and 0 - 11 for PTSD with higher scores reflecting more problems, greater stress, and more symptoms of PTSD. Using mean substitution, one additional participant's data were used in each of the two groups. Means with identical superscripts are significantly different from one another at p < .05 and represent general trends of decreased stress over time.

Table 8

Means and Standard Deviations for the PSI: Parent Domain, Attachment, and Depression

	Parent Domain			Attachment			Depression		
	Total Sample	Intervention	Standard Care	Total Sample	Intervention	Standard Care	Total Sample	Intervention	Standard Care
Time 1 (Baseline)	110.4 ± 27.6	103.9 ± 27.4	116.4 ± 27.6	12.2 ± 3.4	11.1 ± 3.1	13.3 ± 3.5^b	18.1 ± 5.9	16.4 ± 6.4	19.7 ± 5.2
n	21	10	11	21	10	11	21	10	11
%ile rank	30th	22nd	42nd	50th	35th	65th	35th	25th	47th
[Coefficient alpha]	[.71]			[.74]			[.84]		
Time 6 (Day +21)	$107.4 \pm 23.5^*$	$100.1 \pm 20.1^*$	114.6 ± 24.7	$11.1 \pm 3.1^*$	11.2 ± 3.9	$11.0 \pm 2.3^{b*}$	$15.6 \pm 4.8^*$	$15.3 \pm 5.2^*$	$15.8 \pm 4.7^*$
n	20	10	10	20	10	10	20	10	10
%ile rank	25th	17th	38th	35th	35th	35th	18th	16th	19th
[Coefficient alpha]	[.81]			[.62]			[.80]		
Normative Sample[a]	123.1 ± 24.4, N = 2,633			12.7 ± 3.2, N = 2,633			20.3 ± 5.5, N = 2,633		

Note. Possible scores range from 54 - 270 for the Parent Domain, 7 - 35 for Attachment, and 9 - 45 for Depression with higher scores indicating greater stress. Means with identical letter superscripts are significantly different from one another at $p < .05$ and represent general trends of decreased stress over time. * Significantly different from normative sample ($p < .05$). [a]Normative sample from Abidin, 1995.

Table 9

Means and Standard Deviations for the PSI: Competence, Spouse, and Isolation

	Competence			Spouse			Isolation		
	Total Sample	Intervention	Standard Care	Total Sample	Intervention	Standard Care	Total Sample	Intervention	Standard Care
Time 1 (Baseline)	29.5 ± 7.0[b]	28.9 ± 7.4	30.1 ± 6.9	16.6 ± 6.6	14.5 ± 6.7	18.6 ± 6.1	12.9 ± 5.0	11.8 ± 5.2	13.8 ± 4.8
n	21	10	11	21	10	11	21	10	11
%ile rank	59th	55th	60th	53rd	37th	68th	59th	47th	67th
[Coefficient alpha]	[.72]			[.87]			[.82]		
Time 6 (Day +21)	26.1 ± 5.9[b,*]	25.5 ± 6.3[*]	26.9 ± 5.6	17.7 ± 6.7	15.7 ± 6.0	19.7 ± 7.1	11.4 ± 3.8	9.6 ± 2.6[*]	13.2 ± 4.1
n	20	10	10	20	10	10	20	10	10
%ile rank	35th	33rd	39th	62nd	47th	73rd	42nd	21st	62nd
[Coefficient alpha]	[.70]			[.81]			[.76]		
Normative Sample[a]	29.1 ± 6.0, N = 2,633			16.9 ± 5.1, N = 2,633			12.6 ± 3.7, N = 2,633		

Note. Possible scores range from 13 - 65 for Competence, 7 - 35 for Spouse, and 6 - 30 for Isolation with higher scores indicating greater stress. Means with identical letter superscripts are significantly different from one another at p < .05 and represent general trends of decreased stress over time. [a] Normative sample from Abidin, 1995. [*] Significantly different from normative sample (p < .05).

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Table 10

Means and Standard Deviations for the PSI: Health and Role Restriction

	Health			Role Restriction		
	Total Sample	Intervention	Standard Care	Total Sample	Intervention	Standard Care
Time 1 (Baseline)	11.4 ± 3.9	10.6 ± 4.2	12.2 ± 3.8	18.0 ± 6.6^{b}	16.1 ± 5.4	19.6 ± 7.4
n	21	10	11	21	10	11
%ile rank	57th	45th	67th	45th	31st	62nd
[Coefficient alpha]	[.73]			[.91]		
Time 6 (Day +21)	10.9 ± 3.2	10.0 ± 3.4	11.7 ± 3.0	$14.7 \pm 5.0^{b,*}$	$13.1 \pm 5.1^{*}$	16.3 ± 4.6
n	20	10	10	20	10	10
%ile rank	48th	35th	63rd	23rd	16th	33rd
[Coefficient alpha]	[.67]			[.76]		
Normative Sample[a]	11.7 ± 3.4, N = 2,633			18.9 ± 5.3, N = 2,633		

Note. Possible scores range from 5 - 25 for Health and 7 - 35 for Role Restriction with higher scores indicating greater stress. Means with identical letter superscripts are significantly different from one another at p < .05, and represent general trends of decreased stress over time. [a]Normative sample from Abidin, 1995. [*] Significantly different from normative sample (p < .05).

Table 11

PSI Percent Change Scores: Parent Domain, Attachment, and Depression

Group	Subject Number	Parent Domain[a]			Attachment[b]			Depression[c]		
		Non-non (same)	Non-clin (worse)	Clin-non (better)	Non-non (same)	Non-clin (worse)	Clin-non (better)	Non-non (same)	Non-clin (worse)	Clin-non (better)
Intervention (n=9)*		9 (100)	0 (0)	0 (0)	7 (78)	1 (11)	1 (11)	8 (89)	1 (11)	0 (0)
	100	X			X			X		
	101	X			X			X		
	105	X			X			X		
	112	X				X		X		
	115	X			X			X		
	118	X			X				X	
	120	X					X	X		
	121	X			X			X		
	122	X			X			X		
Standard Care (n=10)*		9 (90)	1 (10)	0 (0)	9 (90)	0 (0)	1 (10)	8 (80)	0 (0)	2 (20)
	102	X			X			X		
	103	X			X			X		
	104	X			X			X		
	106		X		X					X
	107	X					X	X		
	108	X			X			X		
	109	X			X			X		
	113	X			X			X		
	116	X			X					X
	119	X			X			X		

Note. *Data are n (%) based on number of subjects within each group. One death and one set of incomplete data occurred in the Intervention group. One dropout occurred in the Standard Care group. PSI norms taken from Abidin (1995); ≥ 85th %ile. [a]M=123.1, SD=24.4, cutoff ≥ 148; [b]M=12.7, SD=3.2, cutoff ≥ 16; [c]M=20.3, SD=5.5, cutoff ≥ 26.

Table 12

PSI Percent Change Scores: Competence, Spouse, and Isolation

	Competence[a]				Spouse[b]				Isolation[c]			
Group / Subject Number	Non-non-clin (same)	Clin-clin (same)	Non-clin-clin (worse)	Clin-non-clin (better)	Non-non-clin (same)	Clin-clin (same)	Non-clin-clin (worse)	Clin-non-clin (better)	Non-non-clin (same)	Clin-clin (same)	Non-clin-clin (worse)	Clin-non-clin (better)
Intervention (n=9)*	8 (89)	0 (0)	0 (0)	1 (11)	7 (78)	1 (11)	0 (0)	1 (11)	8 (89)	0 (0)	0 (0)	1 (11)
100	X				X				X			
101				X	X				X			
105	X				X				X			
112	X				X							X
115	X					X			X			
118	X				X				X			
120	X				X				X			
121	X				X				X			
122	X							X	X			
Standard Care (n=10)*	8 (80)	0 (0)	1 (10)	1 (10)	6 (60)	2 (20)	1 (10)	1 (10)	7 (70)	1 (10)	1 (10)	1 (10)
102	X				X				X			
103	X				X				X			
104	X						X			X		
106				X	X						X	
107	X				X				X			
108	X				X				X			
109			X					X				X
113	X					X			X			
116	X					X			X			
119	X				X				X			

Note. *Data are n (%) based on number of subjects within each group. One death and one set of incomplete data occurred in the Intervention group. One dropout occurred in the Standard Care group. PSI norms taken from Abidin (1995): ≥ 85th %ile. [a] M=29.1, SD=6.0, cutoff ≥ 35; [b] M=16.9, SD=5.1, cutoff ≥ 22; [c] M=12.6, SD=3.7, cutoff ≥ 17.

Table 13

PSI Percent Change Scores: Health and Role Restriction

Group	Subject Number	Health[a] Non-non (same)	Clin-clin (same)	Non-clin (worse)	Clin-non (better)	Role Restriction[b] Non-non (same)	Clin-clin (same)	Non-clin (worse)	Clin-non (better)
Intervention (n=9)*		8 (89)	1 (11)	0 (0)	0 (0)	9 (100)	0 (0)	0 (0)	0 (0)
	100	X				X			
	101	X				X			
	105	X				X			
	112	X				X			
	115		X			X			
	118	X				X			
	120	X				X			
	121	X				X			
	122	X				X			
Standard Care (n=10)*		8 (80)	1 (10)	0 (0)	1 (10)	7 (70)	1 (10)	0 (0)	2 (20)
	102	X				X			
	103	X				X			
	104	X					X		
	106		X			X			
	107	X				X			
	108	X				X			
	109				X	X			
	113	X				X			
	116	X							X
	119	X							X

Note. *Data are n (%) based on number of subjects within each group. One death and one set of incomplete data occurred in the Intervention group. One dropout occurred in the Standard Care group. PSI norms taken from Abidin (1995): ≥ 85th %ile. [a]M=11.7, SD=3.4, cutoff ≥ 16; [b]M=18.9, SD=5.3, cutoff ≥ 24.

Table 14

Means and Standard Deviations for the WCQ: Confrontive, Distancing, and Self-Controlling

	Confrontive			Distancing			Self-Controlling		
	Total Sample	Intervention	Standard Care	Total Sample	Intervention	Standard Care	Total Sample	Intervention	Standard Care
Time 1 (Baseline)	4.4 ± 2.7[a]	5.3 ± 3.2	3.6 ± 2.1	3.7 ± 3.1	4.1 ± 3.0	3.4 ± 3.2	6.7 ± 4.4	5.1 ± 3.6	8.0 ± 4.8
n	21	10	11	21	10	11	21	10	11
[Coefficient alpha]	[.33]			[.55]			[.75]		
Time 6 (Day +21)	2.9 ± 1.6[a]	3.0 ± 1.8	2.8 ± 1.4	3.3 ± 1.9	3.6 ± 2.1	2.9 ± 1.8	5.8 ± 4.0	7.8 ± 2.1	5.3 ± 4.1
n	19	9	10	19	9	10	20	10	10
[Coefficient alpha]	*			[.42]			[.63]		

Note. Possible scores range from 0 - 18 for Confrontive, 0 - 18 for Distancing, and 0 - 21 for Self-Controlling with higher scores reflecting more frequent use of coping strategies. Means with identical superscripts are significantly different from one another at p < .05. *Reliability coefficient could not be computed due to low frequency of item endorsement.

Table 15

Means and Standard Deviations for the WCQ: Seeks Social Support, Accepting Responsibility, and Escape-Avoidance

	Seeks Social Support			Accepting Response			Escape-Avoidance		
	Total Sample	Intervention	Standard Care	Total Sample	Intervention	Standard Care	Total Sample	Intervention	Standard Care
Time 1 (Baseline)	8.3 ± 3.2	9.2 ± 3.9	7.6 ± 2.4	1.5 ± 1.8	1.0 ± 1.5	1.9 ± 2.0	8.7 ± 4.9^b	8.4 ± 4.1	8.9 ± 5.8
n	21	10	11	21	10	11	21	10	11
[Coefficient alpha]	[.39]			[.23]			[.70]		
Time 6 (Day +21)	7.3 ± 4.6	6.3 ± 4.0	6.8 ± 4.5	0.9 ± 1.3	1.3 ± 1.4	0.4 ± 1.0	5.5 ± 3.5^b	5.0 ± 3.0	5.9 ± 4.0
n	19	9	10	19	9	10	20	10	10
[Coefficient alpha]	[.80]			[.18]			[.61]		

Note. Possible scores range from 0 - 18 for Social Support, 0 - 12 for Accepting Responsibility, and 0 - 24 for Escape-Avoidance with higher scores reflecting more frequent use of coping strategies. Means with identical superscripts are significantly different from one another at p < .05.

Table 16   77

Means and Standard Deviations for the WCQ: Problem Solving and Positive Reappraisal

	Problem Solving			Positive Reappraisal		
	Total Sample	Intervention	Standard Care	Total Sample	Intervention	Standard Care
Time 1 (Baseline)	5.6 $\pm$ 2.4	5.1 $\pm$ 1.9	6.3 $\pm$ 2.7	10.9 $\pm$ 3.8	11.1 $\pm$ 4.0	10.6 $\pm$ 3.9
n	21	10	11	21	10	11
[Coefficient alpha]	*			[.51]		
Time 6 (Day +21)	6.2 $\pm$ 3.6	6.4 $\pm$ 3.7	5.6 $\pm$ 3.6	11.3 $\pm$ 5.7	14.1 $\pm$ 4.7[a]	5.9 $\pm$ 3.6[a]
n	19	9	10	19	9	10
[Coefficient alpha]	[.68]			[.86]		

Note. Possible scores range from 0 - 18 for Problem Solving and 0 - 21 for Positive Reappraisal with higher scores reflecting more frequent use of coping strategies. Means with identical superscripts are significantly different from one another at p < .05. *Reliability coefficient could not be computed due to low frequency of item endorsement.

Table 17   78

Means and Standard Deviations for the WCQ:
Positive and Negative Coping Composite Scores

	Positive Coping			Negative Coping		
	Total Sample	Intervention	Standard Care	Total Sample	Intervention	Standard Care
Time 1 (Baseline)	10.9 ± 3.6	36.9 ± 10.5	38.0 ± 9.2	11.4 ± 5.5^a	12.6 ± 3.8	12.3 ± 7.8
n	21	10	11	21	10	11
Time 6 (Day +21)	11.3 ± 5.8	38.9 ± 15.7	29.7 ± 16.3	8.9 ± 5.0^a	8.7 ± 4.6	8.8 ± 5.5
n	19	9	10	19	9	10

Note. Higher scores indicate more frequent use of coping strategies. Means with identical superscripts are significantly different from one another at $p < .05$.

Table 18   79

Means and Standard Deviations for the Strategies Checklist: Total Score

	Total Sample	Intervention	Standard Care
Time 2 (Day -7)	9.9 ± 3.7	11.5 ± 2.6	8.3 ± 4.1
n	22	11	11
[Coefficient alpha]	[.88]		
Time 3 (Day 0)	10.1 ± 3.6	11.9 ± 2.2	8.4 ± 3.9
n	22	11	11
[Coefficient alpha]	[.86]		
Time 4 (Day +7)	9.6 ± 3.9	11.2 ± 3.7	8.0 ± 3.7
n	20	10	10
[Coefficient alpha]	[.88]		
Time 5 (Day +14)	9.5 ± 3.3	10.4 ± 2.8	8.5 ± 3.7
n	20	10	10
[Coefficient alpha]	[.79]		
Time 6 (Day +21)	9.3 ± 3.6	11.2 ± 2.6	7.4 ± 3.7
n	20	10	10
[Coefficient alpha]	[.84]		
Average Strategies	9.8 ± 3.2	11.3 ± 2.4[a]	8.2 ± 3.3[a]
n	22	11	11

Note. Possible scores range from 0 - 14 with higher scores indicating use of a
greater number of strategies. Using mean substitution, one additional
participant's data were able to be used in each of the two groups. Means
with identical superscripts are significantly different from one another at $p < .05$.

Table 19

Correlations for Strategy Use and Illness Severity with DSI and SSINT

	DSI			SSINT	
	Average Impact	Average Event	Average Frequency	Average Specific Stress	PTSD, Time 6
Average Strategy Score	-.03 (21)	.14 (21)	-.12 (22)	-.21 (22)	-.07 (20)
Average Parent Rated Illness Severity	-.01 (21)	.07 (21)	-.30 (22)*	-.53 (22)[a]	-.27 (20)
Average BMTU staff Rated Illness Severity	-.38 (17)*	-.35 (17)*	-.34 (18)*	-.16 (18)	.01 (17)
Disease Length	-.13 (21)	-.09 (21)	.04 (22)	.10 (22)	-.02 (20)

Note. Data are r (n). Illness Severity scores range from 0 - 5 with higher scores indicating better health. Strategy scores range from 0 - 14 with higher strategy scores representing greater use of strategies. For the DSI, data do not include the participant considered to be an outlier. [a] Represents p < .05. * Represents p < .05 and are one-tailed. P values are uncorrected and are one-tailed. [a] Represents a trend, p < .10.

Table 20

Correlations for Strategy Use and Illness Severity with PSI Subscales

	Attachment	Competence	Depression	Health	Isolation	Role Restriction	Spouse	Parent Domain
Average Strategy Score	-.05 (20)	-.06 (20)	.15 (20)	.03 (20)	-.36 (20)[a]	-.24 (20)	-.05 (20)	-.11 (20)
Average Parent Rated Illness Severity	-.09 (20)	-.23 (17)	-.10 (20)	-.20 (20)	-.19 (20)	-.07 (20)	.22 (20)	-.12 (20)
Average BMTU Staff Rated Illness Severity	-.21 (17)	-.30 (20)*	-.29 (17)	.03 (17)	-.00 (17)	.13 (17)	.07 (17)	-.08 (17)
Disease Length	-.30 (20)*	.13 (20)	-.14 (20)	.01 (20)	-.31 (20)	-.14 (20)	-.17 (20)	-.16 (20)

Note. Data are r (n). Illness Severity scores range from 0 - 5 with higher scores indicating better health. Strategy scores range from 0 - 14 with higher strategy scores representing greater use of strategies. P values are uncorrected and are one-tailed. [a] Represents a trend, p < .10.

Table 21

Correlations for Strategy Use and Illness Severity with WCQ Subscales

	Confrontive	Distancing	Self-Controlling	Seeks Social Support	Accepting Responsibility	Escape-Avoidance	Problem Solving	Positive Reappraisal	Positive Coping Composite	Negative Coping Composite
Average Strategy Score	.08 (20)	.24 (20)	.45 (20)*	.48 (20)*	.46 (20)*	-.10 (20)	.30 (20)[a]	.50 (20)*	.53 (20)**	.02 (20)
Average Parent Rated Illness Severity	-.18 (20)	.14 (20)	.12 (20)	.19 (20)	.46 (20)*	-.20 (20)	.34 (20)[a]	.17 (20)	.23 (20)	-.09 (20)
Average BMTU Staff Rated Illness Severity	-.47 (17)*	-.10 (17)	-.32 (17)[a]	-.06 (17)	-.14 (17)	.09 (17)	-.21 (17)	-.13 (17)	-.22 (17)	.02 (17)
Disease Length	-.01 (20)	.23 (20)	.06 (20)	.22 (20)	.35 (20)	.08 (20)	-.24 (20)	.21 (20)	.12 (20)	.15 (20)

Note. Data are r (n). Illness Severity scores range from 0 - 5 with higher scores indicating better health. Strategy scores range from 0 - 14 with higher strategy scores representing greater use of strategies. P values are uncorrected and are one-tailed. * $p < .05$, **$p < .01$. [a] Represents a trend, $p < .10$.

Table 22
83

Means and Standard Deviations for the Knowledge Questionnaire

	Total Sample	Intervention	Standard Care
Time 1 (Baseline)	9.1 ± 2.2^a	9.3 ± 1.9	9.0 ± 2.5
n	21	10	11
[Coefficient alpha]	[.37]		
Correlation between Knowledge and Strategy	-.01 (22)		
Time 2 (Day -7)	10.2 ± 1.9^a	10.3 ± 2.1	10.2 ± 1.8
n	22	11	11
[Coefficient alpha]	[.56]		
Correlation between Knowledge and Strategy	-.10 (22)		

Note. Data are presented r (n). Possible scores range from 0 - 12 with higher scores indicating greater knowledge. Correlations are using two-tailed bivariate correlations. Means with identical superscripts are significantly different from one another at p < .05.

Table 23

84

Means and Standard Deviations for Illness Severity

	Parent Rated			BMTU Staff Rated		
	Total Sample	Intervention	Standard Care	Total Sample	Intervention	Standard Care
Time 1 (Baseline)	$4.3 \pm .97^{a,b,c}$	$4.6 \pm .67$	4.0 ± 1.2			
n	21	11	10			
Time 2 (Day -7)	$3.6 \pm .94^{a,d}$	$4.1 \pm .77$	3.4 ± 1.1	$4.1 \pm .90$	$4.0 \pm .89$	$4.1 \pm .96$
n	22	11	11	16	6	9
Time 3 (Day 0)	$3.6 \pm .94^{b,e}$	3.8 ± 1.1	$3.4 \pm .77$	$3.9 \pm .76$	$4.1 \pm .94$	$3.9 \pm .66$
n	21	10	11	18	8	9
Time 4 (Day +7)	$3.5 \pm 1.0^{c,f,g}$	$3.9 \pm .93$	$3.2 \pm .98$	$3.2 \pm .94$	3.0 ± 1.0	$3.4 \pm .89$
n	19	9	10	12	7	5
Time 5 (Day +14)	$3.8 \pm .97^{f,h}$	4.0 ± 1.0	$3.6 \pm .91$	$4.1 \pm .76$	$4.2 \pm .70$	$3.7 \pm .76$
n	19	9	10	13	7	5
Time 6 (Day +21)	$4.5 \pm .69^{d,e,g,h}$	$4.6 \pm .52$	$4.3 \pm .82$	$4.5 \pm .66$	$4.4 \pm .79$	$4.6 \pm .55$
n	20	10	10	12	7	5
Average Score	$3.7 \pm .74$	$4.0 \pm .74$	$3.5 \pm .66$	$4.0 \pm .57$	$4.0 \pm .60$	$3.9 \pm .55$
n	22	11	11	19	9	10

Note. Scores range from 0 - 5 with higher scores reflecting perceptions of better health of the child. Means with identical superscripts are significantly different from one another at $p < .05$.

DISCUSSION

This study examined the efficacy of a newly designed intervention program for parents of children undergoing bone marrow transplantation (BMT). While several studies have examined the stress of parents of children in a hospital or medical procedure setting, only a handful of investigations have included parents in intervention programs, and none of these previously published studies has specifically focused on parents of children undergoing BMT. This study used an experimental design with two groups: Intervention and Standard Care. Levels of stress of participants in each of the two groups were compared, and it was hypothesized that the Intervention group would report lower levels of stress as measured by two standardized self-report questionnaires and one semi-structured interview. Parents' coping strategies and use of intervention techniques were also examined, as were participants' knowledge relevant to intervention information and ratings of illness severity. The relationships between these variables and outcome measures of stress were examined.

Reliability Analyses

Results of this study support the internal consistency of the two previously standardized measures of stress: Daily Stress Inventory (DSI) and Parenting Stress Index (PSI). The other measure of stress, the semi-structured interview (SSINT), also had adequate reliability. Alpha coefficients for the SSINT Change and Problem scores and for the Strategies checklist total score were not computed given that all items did not require a response. The Knowledge Questionnaire had poor reliability. Upon further

examination of its reliability, removing one item on administration at Time 1 (a question which was awkwardly worded), significantly increased reliability. However, even with this item deletion, reliability for the Knowledge Questionnaire remained poor (alpha = .50).

The Ways of Coping Questionnaire (WCQ) did not have adequate reliability for several of its subscales. This measure has been standardized, and multiple variations of its form have been used in response to several different factor interpretations (Aldwin et al., 1980; Vitaliano et al., 1985). Participants rated the frequency of use of coping strategies, and for several subscales, variability was quite limited. This likely affected the internal consistency of the measure. In fact, for two subscales, alpha coefficients could not be computed due to low rates of item endorsement. Low reliability estimates in this study as compared to previous reports of the WCQ could be due in part to the small sample size.

<div align="center">Demographics</div>

The two groups were similar in demographic characteristics. Mothers were well educated and represented a wide range of marital status (married, single, divorced, widowed, and separated). Diversity of ethnicity was relatively limited with only three non-Caucasian mothers and four non-Caucasian children. However, these ethnicity characteristics are representative of all children undergoing BMT at Shands. Children were, on average, in the middle age range of the selection criteria (2-16 years). Boys were more represented than were girls. Illness characteristics were quite diverse, with both cancerous and non-cancerous disorders represented in each group, as well as four different types of transplant in each of the two groups. Such variation of illness type and

transplant method is quite common for the BMTU at Shands. Similarly, time since diagnosis and number of previous hospitalizations varied greatly. This was expected given that children undergo BMT at various times in their treatment which is typically dependent on specific disease characteristics. Demographics of this sample are representative both of families of children undergoing BMT at Shands and of those reported in the literature (Phipps & DeCuir-Whalley, 1990; Pinkel, 1993). The sample is therefore considered to be representative of other BMT centers.

<div align="center">Missing Data</div>

As noted previously, two participants did not complete data collection through Time 6 (one dropout and one child's death). Data from these participants were used through the time point when measures were completed, yet substitutions for the remainder of their data assessments were not used. For participants with missing data at one or two Time points in the midst of data collection, group means were substituted to increase the amount of data retained for analyses (Nich & Carroll, 1997). Given the overall findings of distinct differences between Time 1 and other assessment points, with data collected between Times 2 and 5 having few differences, mean substitution for missing assessments occurring between Times 2 and 5 are not likely to have had a large impact on findings.

<div align="center">Measures of Stress</div>

Contrary to the study's main hypothesis, examining levels of stress through both self-report measures and interview did not show that participants in the Intervention group experienced significantly less stress than participants in the Standard Care group. Other investigations with small sample sizes of chronically ill children/parents have also

failed to yield statistically significant differences between intervention and control conditions (Robinson & Kobayashi, 1991). Possible explanations for findings in the current study are explored below.

<u>Daily Stress Inventory</u>

In examining DSI scores as compared to normative samples, several interesting observations were made. There was one significant difference in the direction of the current study's sample having more stress than the normative sample: the total event score at Time 1. All other findings consistently showed this sample as reporting less stress than the normative sample, suggesting that overall, participants endorsed relatively low levels of stress.

Similarly, in examining percent change scores for the DSI, relatively few participants began (Time 1) or ended (Time 6) in the clinical range, limiting the ability to examine group differences. Two individuals moved from clinical to non-clinical ranges for DSI Impact scores, and more background information related to their specific situations are described below.

The following is a brief case description of a prototypical participant from the Intervention group:

> The participant in the Intervention group whose score improved for DSI Impact actually had a worse score for the DSI event scale, moving from the non-clinical to clinical range. At Time 1, this participant indicated having a low number of daily stressors (event) which caused a significant amount of stress (impact). By the end of three weeks post-transplant, she endorsed a greater number of daily stressors (event score in the clinical range), however, she indicated that they were not as stressful to her (non-clinical impact score). Anecdotally, this participant was one who, at baseline and during the intervention session, reported that many of the little stressors were "adding up" and that she was not sure how she would be handling her daughter's long hospitalization. Her daughter had been an

inpatient on a regular medical floor for several months prior to her BMTU admission. The participant had been waiting for her child to be medically ready for BMT. During the intervention session, the participant indicated having particular difficulty taking care of herself through the current hospitalization (i.e., eating, sleeping, relaxing), and these areas were discussed as part of the intervention. Of interest, this participant was seen walking or exercising on several occasions during her child's BMTU stay. While her child had many medical ups and downs on the BMTU, the participant's scores suggest that she was handling the demands better by the end of hospitalization, although she did continue to have multiple daily stressors.

Below is another case description that exemplifies the process of preparing for

BMT of one participant in the Standard Care group:

The participant in the Standard Care group with improvements from clinical to non-clinical ranges for both the Impact and Event scores was one who was noted to be quite overwhelmed pre-admission. This parent had a young child with a long history of illness and multiple previous hospitalizations. This participant's child was also an inpatient on a medical floor prior to BMTU admission, and had actually been an inpatient for several consecutive months. During the baseline assessment, the participant indicated high levels of distress and significant uncertainty as to what the BMTU hospitalization entailed, beyond current and past hospitalizations. Furthermore, this participant's child had a non-cancerous illness for which few previous BMTs had been performed. No formal preparation aside from standard care was provided given group assignment. However, an intern from the psychology department had been following this child (with some support provided to the participant) for several weeks prior to BMTU admission. This family was also noted to have significant amounts of social support, as well as an established relationship with several health care professionals given the child's lengthy hospital stay. As noted above, scores for both Impact and Event were non-clinical at Time 6.

Although no Group differences emerged for the DSI, there were several main

effects for Time, supporting the hypothesis that parents' stress changes over time. This

seems logical given that parents with children on a BMTU are continuously reacting to

alterations in their environment including changes in their child's medical status,

psychological adjustment, and overall differences in the unit (i.e., other children being discharged or even dying).

Similar to findings reported in the literature, parents in this sample generally reported greater levels of stress pre-transplant than once the transplant occurred (Rodrigue et al., 1996). Reports of stress for Time 1 for both Impact and Event scores were significantly higher than at Times 4 and 5 (Impact) and Times 2, 3, 4, and 5 (Event). In considering these reports of stress in relation to the BMT medical process, Impact scores remained similar to stress levels pre-admission during the intensive chemotherapy/TBI and actual transplant stages, decreased somewhat during the waiting for engraftment process, and increased slightly several weeks post-transplant at a time infections and other side effects are most common. Time 6 also includes the time period during which families are preparing for discharge which can be quite stressful as parents begin to assume more of the nursing role (McConville et al., 1990, White, 1994).

Specific to findings from the DSI, the effects for Time were quite robust, with significantly greater stress reported at Time 1. While it could be argued that changes in stress were a result of regression towards the mean, such an explanation is unlikely given that the DSI has been used repeatedly and has been found to be sensitive to change and resistant to practice effects (Brantley et al., 1987). Furthermore, the changes seen in this investigation were evident for the entire sample, as well as for other measures of stress.

Parenting Stress Index

Similar to results from the DSI, comparisons between this sample's PSI scores and the published normative sample (Abidin, 1995) indicate that participants in this sample were experiencing low levels of stress. Again, this highlights the level at which

participants were when they began involvement in this study. Given the relatively low levels of stress reported pre-transplant, there may have been little room for improvement, limiting the possibility of finding group differences or changes over time. Parents undergoing such a stressor are likely considering the significant difficulties that lie ahead, and may try to pull themselves together, thereby minimizing reported stress. However, in a study of another group of parents of children undergoing BMT (Rodrigue et al., 1996), parents' reported stress on the PSI was higher than that reported by the normative sample. These discrepant findings are particularly interesting given that the current study's sample and the sample from Rodrigue et al. (1996) were from the same BMT center. It is possible that with BMTs becoming more common and resulting in higher rates of survival, the overall experience for parents is much different today than it was even 5-6 years ago.

Percent change scores were limited in variability, with the majority of participants beginning and ending in the non-clinical ranges for most subscales. Several cases from participants in the Standard Care group are presented below; there were few overall changes in the Intervention group.

> One participant in particular was reportedly undergoing significant stress aside from her child's BMT (i.e., recent divorce, financial difficulties). This participant's score on the PSI worsened from the non-clinical to clinical range for two subscales: Spouse and Isolation. Her scores likely represent changes in her life aside from those directly related to her child's BMT hospitalization.

> A different participant remained in non-clinical ranges for three of the subscales and improved from clinical to non-clinical ranges on four subscales (Isolation, Role Restriction, Spouse, Health), and declined from a non-clinical to clinical range for Competence. This participant had another very young child at home, lived several hours from the hospital, and at the time of baseline, was uncertain as to who would be caring for

her other child while the ill child underwent BMT. Similarly, she seemed to have concerns about her husband's work schedule, being uncertain about how often he would have the opportunity to be at the hospital. During several data collection times it was noted that her husband was present in her child's hospital room. The participant's uncertainty pre-admission likely impacted her ratings of stress, and having more support during the BMTU hospitalization than she had previously anticipated may have affected her decreased ratings of stress at three weeks post-transplant.

As noted earlier, no group differences emerged for the PSI. There was one significant interaction for Attachment, with participants in the Standard Care group reporting greater levels of Attachment-related stress pre versus post-transplant. Similar to the DSI, there were two noted Time effects (Competence and Role Restriction) representing significantly greater levels of stress at Time 1 versus Time 6. After having grown accustomed to the BMTU and general BMT process, it is understandable that parents would indicate feeling more competent at Time 6 than pre-admission. The finding for Role Restriction may be due in part to parents actually having greater support and more ability to take care of their own needs than previously anticipated.

Semi-Structured Interview

No Group or Time effects were found for the frequency, problem, or change scores. Reliabilities for the frequency scale were adequate, particularly given that the measure had not been used previously. Internal consistency for the problem and change scores could not be calculated given that responses were dichotmous (yes/no). In considering the SSINT, the problem and change questions were, at times, difficult to explain to parents. Frequency data focused on physiological symptoms associated with stress; occurrence of these symptoms was reportedly quite low, possibly another reason why changes in time or group differences might have been difficult to detect.

The Specific stress score from the SSINT was the only measure of stress in this investigation that was particularly relevant to parenting a hospitalized child. Consistent with findings from other measures, stress was greater at pre-admission than once the child was on the BMTU, with more significant differences noted in the Intervention group. Differences at Time 1 are actually even greater than determined by analyses given that for several participants, questions asked at pre-admission were not relevant, and therefore received the lowest rating of stress. Such items included stress during mouth care which several children had not yet undergone prior to BMT.

In contrast to other studies that have examined and confirmed symptoms of post-traumatic stress present in children and adults involved in cancer treatment (Kazak et al., 1997; Lee et al., 1994; Stuber et al., 1991), the PTSD portion of the SSINT used in this sample did not reveal significant findings. Participants endorsed an average of 3.3 out of 11 symptoms that were closely worded to DSM-IV diagnostic criteria. Other studies have used measures more relevant to this population which may account for greater endorsement of such symptomatology. In addition, parents responded to the PTSD questions at one time point only, three weeks post-transplant. It is possible that because many parents were still living the experience of BMT, with children in the hospital at this time point, PTSD symptomatology was less relevant.

Overall Findings from Measures of Stress

Lazarus and Folkman's transactional theory of stress (1984) is useful in considering the overall findings from the three measures of stress which strongly support the decline of stress from pre to post transplant. Stress is defined as an event or situation that is appraised as taxing or exceeding one's resources. In other words, events or

situations (such as BMT) are not inherently stressful. Rather, it is the meaning that the individual assigns to the event/situation that determines the experience of stress. At baseline, participants had little personal experience with BMT. They were likely to have "imagined the worst" or may have simply feared the unknown. BMT may therefore have been considered or appraised as extremely stressful at pre-admission. While hospitalization progressed, however, the meaning assigned to BMT likely changed for each participant. Less was unknown as time went on, and participants were more likely to feel less taxed given that they had already gotten through a portion of the hospitalization. It is this appraisal, or changed meaning, that likely had a direct impact on participants' experience of stress.

Ways of Coping Questionnaire

Despite poor reliability of several WCQ subscales as noted previously, several interesting findings emerged. At three weeks post-transplant mothers in the Intervention group used significantly more Positive Reappraisal coping strategies than did mothers in the Standard Care group. There was a similar trend toward a significant interaction for the Problem Solving subscale, with participants in the Intervention group using more strategies at Time 6 than at Time 1, and participants in the Standard Care group using more at Time 1 than at Time 6. Another trend was seen after combining several strategies considered to be Positive, with mothers in the Intervention group using more Positive strategies at Time 6 and mothers in the Standard Care group using more Positive strategies at Time 1 versus Time 6. These trends and the significant interaction for Positive Reappraisal are in the expected direction and suggest that participants in the

Intervention group may have altered several coping strategies post-intervention. These findings offer support for the effectiveness of the intervention.

While coping may be associated with outcome, the process through which coping impacts upon stress is unclear. Several findings from this sample are consistent with the literature on coping with childhood chronic illness within the family as well as coping with medical difficulties within the adult literature. Encapsulation has been considered to be play a mediating role in the experience of stress within families with a chronically ill child (Birenbaum, 1990). Encapsulation includes factors associated with appraisal of a situation such as the families ability to normalize the illness and also attach meaning to the illness experience. Participants endorsing the use of Positive Reappraisal strategies were likely attaching more positive meanings to their child's BMT.

Within the adult literature, using a greater number of problem vs. emotion focused coping strategies has been associated with a more positive adjustment to illness. Several of the strategies classified as "positive" for this sample were problem-focused, however, groups in this sample did not differ on use of problem-focused strategies, in particular, and no differences in use of problem-focused strategies were found over time. This suggests that parents of children undergoing a specific medical stressor may benefit from a different combination of coping strategies than if handling their own illness or treatment. Greater understanding of the particular types of coping strategies most helpful to parents can be gained only through further investigations.

Similar to measures of stress, several Time effects were noted on the WCQ, with all but one in the expected direction of participants using more positive strategies at Time 6 versus pre-admission, Time 1. The unexpected finding was for the Confrontive

subscale which indicated less use at Time 6 than at Time 1 for both groups. Questions related to the Confrontive subscale may have been more relevant for parents at Time 1, a time when there are many uncertainties about the child's treatment since they had not yet been admitted the BMTU. Again, regression towards the mean could be considered as a possible explanation for findings on the WCQ. However, changes in different directions illustrated for different subscales suggests that differences are instead due to the experience of the BMT process.

<div align="center">Use of Intervention Techniques</div>

Knowledge Questionnaire

The intervention incorporated three main areas (communication, education, and relaxation) and covered many more topics considered particularly relevant for families experiencing the stress of preparing for BMT. The Knowledge Questionnaire was designed to assess changes in understanding from pre to post intervention, as well as to see general level of understanding in the Standard Care group. However, there was such little variability in the measure resulting in a ceiling effect. There are several possible explanations for the increase in knowledge seen at Time 2 versus Time 1. First, parents' high levels of stress may have interfered with comprehension or concentration in completing the measure at baseline. Second, once their child had been admitted to the BMTU, much vicarious learning likely took place through interactions with parents of other children on the unit, physicians, or other BMTU staff. Third, it is possible that the demand characteristics associated with being a parent of a child on the BMTU impacted parents' knowledge of ways in handling the BMTU experience.

BMT centers typically do not assess parents' knowledge related to the BMT process. Furthermore, aside from prior to discharge, little effort is made to understand parents' knowledge of actual medical regimen procedures. While it seems logical that having more knowledge about how to assist one's child throughout hospitalization would be of benefit, an assessment of such knowledge does not seem to be a necessary component of the BMT admission process. However, more formally assessing medical aspects (i.e., procedures to be carried out, suppressed immune system, etc.) may be helpful in assisting parents through the typically stressful time of the child's discharge.

Strategies

The purpose of the Strategy checklist was twofold: (1) to assess participants' use of intervention techniques on an ongoing basis, and (2) to provide a simple reminder to parents in the Intervention condition of strategies learned during the intervention session. Participants in the Intervention condition reported the use of significantly more Strategies than participants in the Standard Care condition. Use of the checklist as a reminder to parents was not formally assessed.

Aside from a few noted trends with measures of the DSI, no significant relationships were found between average Strategy use and measures of stress. There were, however, several significant findings between use of Strategies and WCQ subscales indicating that participants using more intervention Strategies were more likely to also endorse using positive coping strategies as measured by the WCQ. This seems logical given that the Strategy checklist can be considered a short "list of ways of coping specifically with a child's BMT hospitalization," containing items relevant to both problem and emotion focused coping. The significant correlations between Strategies

and the WCQ again suggest that the intervention program targeted participants' coping strategies.

<div align="center">Illness Severity</div>

Parent Rated

The role of illness severity in examining psychosocial adjustment to chronic illness and treatments has been explored repeatedly with generally equivocal findings (Canning et al., 1996; McConville et al., 1990; Youngblut & Shiao, 1993). Within the literature, illness severity has been assessed in multiple ways including using disease characteristics, physician ratings, and parent perception. Given the limited findings in using measures of direct illness or disease characteristics, parent perception was used as the primary assessment in examining the relationship between illness severity and reported levels of stress. It was hypothesized that parents who perceived their children as doing worse medically, regardless of actual disease status, would also indicate having greater levels of stress.

There was little variability in illness severity ratings, with most parents indicating that their child was doing "OK to very well" throughout hospitalization. No significant Group differences were found yet parents in the Intervention group did have a higher average illness severity score, indicating a perception of better medical condition. Investigation of Time resulted in many significant findings supporting the hypothesis found in the literature of medical aspects of BMT occurring in stages (Lesko,1989; Wiley & House, 1988) including TBI, the actual transplant, waiting for engraftment, and possibility of infection.

Examination of the relationship between parent rated illness severity and outcome measures yielded few significant results, not above what would be expected by chance. However, given the limited sample size, definitive conclusions can not be drawn. Several more subscales of the WCQ might have been significant with additional statistical power. Given other results in this sample, it is possible that Positive Reappraisal and Escape Avoidance strategies in particular might be related to how parents perceive their children to be doing medically. For example, parents using denial or avoidant strategies may be less likely to pay attention to indicators of poor health. Similarly, parents who have adopted a more positive outlook and who are coping by using reappraisal may consciously consider their children as doing better than they truly are.

In addition, although reports from the literature suggest few significant relationships between parent reported illness severity and outcome measures, parents in this sample may be particularly prone to rating their child as doing better than they are. First, at the pre-transplant time point, children must be in remission and "healthy enough" to undergo BMT. Parents may therefore see their children as doing well, particularly when compared to previous months when disease was present. Second, during the BMTU process, parents have undoubtedly been told to "expect the worst" and may therefore feel that their child is actually doing well. Third, parents may have an easier time coping with BMT if they believe that their child is doing well, medically.

Anecdotally, in administering the Illness Severity measure on occasions when a child was considered by staff to be in critical condition, several parents were noted to continue endorsing the "OK" Likert point, and were seemingly unwilling to endorse anything suggesting a poorer medical condition. Even in the case of one parent who was

followed while her child was transferred to the Pediatric Intensive Care Unit, the majority of ratings were given an "OK" with only two of seven during the PICU stay being rated as "Very poorly to OK", or a rating of "2" on a scale from "1" to "5". This participant's WCQ scores at Time 6, while her child was still on the PICU, were examined. She indicated using few coping strategies overall, however, she did endorse the use of several positive reappraisal strategies which may have impacted her perception of her child's medical status. Parents' difficulty in reporting objective measures of illness severity may explain the equivocal findings in the literature of the relationship between psychosocial adjustment and illness severity.

BMTU Staff Rated

Parent ratings of illness severity were not significantly correlated with ratings from BMTU staff (i.e., physicians, nurses, and physician assistants), yet overall means were quite similar. Measures from parents and staff undoubtedly come from distinct perspectives, with the parent rating likely to be more subjective. In using parents to rate children's illness severity, several issues must be kept in mind. Perhaps most important is that most parents do not work within a hospital setting, and are therefore likely to use a different frame of reference in rating their child's health than do health care professionals. In addition to their child being their primary guide for making such judgments (as opposed to a large sample of children with similar medical conditions), ratings likely include an emotional component.

Similar to parent ratings of illness severity within this sample, variability for BMTU ratings was limited, with most staff indicating that children were doing "OK to fairly well." However, in contrast to mothers with children who were very medically

compromised, staff ratings of these children did vary, with children transferred to the PICU typically rated as a "1" or "2".

Treatment Integrity

Two independent raters who coded videotaped intervention sessions reported excellent percentages of treatment integrity. This indicates that the intervention designed was the same as the one actually delivered to participants. However, only 27 points were included for raters to code as either present or not present in the tapes; topics considered to be most important, and relevant to all participants, were those that were included.

Summary of Findings

This study is the first of its kind to both administer an intervention designed for parents of children undergoing BMT, and to prospectively measure stress in mothers at weekly intervals from pre to several weeks post-transplantation. Taken together, results from outcome measures documented levels of stress in this population, as well as provided limited support for the efficacy of the intervention designed to decrease stress. Parents in the Intervention group reported the use of significantly more strategies to assist them through the BMT process, and indicated using more positive coping strategies post-intervention when compared to parents who did not receive the intervention. Furthermore, several trends in the data suggest that the intervention may have been found to be effective with a larger sample size or more specific outcome measures. In terms of meaningful descriptive data, several Time effects were noted. Overall findings were generally consistent with results from the literature suggesting that stress is higher pre-versus post- transplantation (Phipps et al., 1995; Rodrigue et al., 1996).

In a prospective investigation of 25 children undergoing BMT, Phipps et al. (1997) found that distress in children and families peaks at one week post-transplant, and then returns to below pre-transplant levels several months post-transplantation. While the current sample's level of stress is clearly greater at pre-transplant than one week post, results can not be closely compared to those from Phipps. Phipps and his colleagues did not measure stress at time points between one-week and several months post-transplant, and it is therefore uncertain as to whether their findings of the specific time line for stress would be similar to findings from the current study. However, general findings from the two samples are consistent in that levels of stress dissipated over time to levels lower than pre-transplant. The current study's finding of lower levels of stress post-transplant is also similar to findings of investigations of levels of stress in parents of children undergoing solid organ transplantations (Rodrigue et al., 1996). In general, the preparation period appears to be quite an intensive and stressful time for parents. In terms of pediatric BMT, this has several clinical implications which are discussed below.

<center>Clinical Implications</center>

These data provide strong support for the notion that the pre-transplantation, and pre-admission time in particular, is a stressful time for parents. Given these findings, clinical interventions aimed at assisting parents during this time are warranted. Although the intervention in this study was administered during this time frame, the intervention was aimed at preparing parents for the entire BMT process, and did not specifically focus on handling current stressors. An intervention tailored to meet parents' pre-admission needs would likely occur several weeks, if not months pre-admission, and could incorporate relaxation and cognitive behavioral strategies, targeting pre-admission stress.

Such an intervention would be most useful if continued throughout the pre-admission process, consistently encouraging parents to utilize strategies.

A second important clinical implication is that while parents are indeed more stressed pre-admission than post-transplant, stress levels are not at clinically significant levels as compared to normative samples. In addition, stress dissipates over time. This suggests that not all parents may be in need of psychological services to assist them in adjusting to, and coping with, the transplantation process. By assessing levels of stress before admission, parents who are in need of services can be targeted, and services provided where appropriate. Such assessments are most likely to be helpful if conducted routinely as part of the general pre- transplantation process. A psychology service affiliated with the BMT center would be most appropriate for carrying out these assessments. The assessment could be a relatively brief evaluation (e.g. one hour) targeting parents' level of stress and current use of coping strategies. Information gathered from both self-report measures and through an interview would be helpful. Without the use of a pre- transplant assessment, if psychological services are declined, one might assume that that the parents are not open to receiving assistance. However, it is equally likely that the parents are coping adequately, and are actually not in need of assistance. Regardless of the assessment process, knowing that services are available if needed should provide additional comfort to parents.

Methodological Considerations

As noted earlier, this study is the first of its kind and therefore provides quite meaningful information. Furthermore, the data were collected from a medically diverse patient population followed prospectively over several weeks. However, there are several

limitations to this investigation, many of which have been noted previously. They are discussed in more detail below.

<u>Sample Size</u>

As with any investigation of childhood BMT, the present sample took much time to accrue (16 months). While the sample size is consistent with, and even somewhat above, reports of similar populations within the literature (Lee et al., 1994; Rodrigue et al., 1996, Stuber et al., 1991), 10 participants in each group (after one dropout) contributed to limited power in computing analyses. While mean substitution was utilized to allow for retention of the maximum amount of information, use of participants' own data for all data points is most preferable. In addition, regression analyses could not be calculated in examining the relationship between strategy use or illness severity and outcome measures given the small sample size. Furthermore, due to the small sample size and few significant findings, corrections for experimenter - wise error were not made.

<u>Group Assignment</u>

There are several concerns about random assignment in general, and with the randomization utilized in this study, in particular. During informed consent procedures prior to baseline assessment, participants were informed of the possibility of being placed in one of two groups. Participants were then randomized. It is possible that simply being told that they were being randomized to one of two conditions (one of which was an added preparation program) may have influenced participants, creating an intervention effect in and of itself. Of interest, aside from comments as to how their participation was

relevant or of benefit to them, participants in the Standard Care condition were not noted to ask for the intervention program.

In terms of the randomization carried out in this investigation, one participant who had been randomly assigned to the Intervention condition was moved to the Standard Care condition because her schedule, coupled with the timing of her child's admission, did not allow for conducting the intervention session prior to the child's transplant. This information was known ahead of hospitalization, and it was therefore decided that she should be in the Standard Care group. No other changes were made, yet after data had been collected for 16 participants, 10 were in the Standard Care group and only six were in the Intervention group. Given the nature of the small sample and projected BMTU admissions, it was decided to enroll the next four participants in the Intervention condition in order to reach 10 in each group, and then begin random assignment again. This was carried out. This could have been avoided by using random assignment with counter balancing as participants were enrolled.

Measurement

There are several issues relevant to measurement in the current study: reliance on self-report, relevance of measures to this population, sensitivity of measures, absence of appropriate normative data, and documentation of other psychological treatment. As with all studies relying on self-report measures, this investigation is limited in that there are no objective data as to the parents' level of stress. The semi-structured interview was used to provide an alternate means for participants to express their symptoms. However, observations or a more formal semi-structured interview were not utilized. It can be argued, however, that parents' self report is more valuable than observations given that it

is the parents' perception of their experience of stress that should be targeted. Another possible objective measure would have been the use of a physiological marker of stress such as cortisol or catecholamines (Baum & Grunberg, 1995).

In examining the literature to determine which measures would be most appropriate for use in this study, no measures specific to childhood BMT, or even parenting a child during a lengthy hospitalization, were found. Measures such as the PSI and DSI were designed for use by the general population, and few if any items were particularly relevant to this sample. In fact, for several items of the DSI, participants were asked to "think beyond the question" in trying to relate the question to their own life. For example, for one item "performed poorly due to others," participants were encouraged to think about their performance of a treatment related task for their child. Even still, several DSI items could not be as easily related to parents in our sample who spent the majority of their time in the child's room or across the street from the hospital in the Ronald McDonald house (e.g., "had difficulty in traffic," "dealt with rude waiter, waitress,..etc.").

The disparity between items on questionnaires and the participants' own feelings of stress was noted by participants on several occasions. In fact, the one participant who dropped out of the investigation prior to the end of data collection stated that the questions had "nothing to do with" her, and that they were actually making her more stressed. There has been a call in the pediatric psychology literature for the development of illness specific assessment tools for use with pediatric populations (La Greca & Lemanek, 1996; Quittner et al., 1996). While a measure examining parental stress related to pediatric BMT may be too specific, a measure of parenting stress during a child's

hospitalization would be useful for both this population as well as for families in which a child is undergoing other treatments or surgeries.

In addition to difficulty with the relevance of the included measures, there is concern for the measures' sensitivity. The DSI and PSI have been used in many investigations with both clinically and statistically significant findings. However, given the small sample size in this study, small changes would have been quite difficult to detect statistically. While the internal consistency of the measures was supported, the measures may not have been sensitive to small but meaningful changes in our sample. This was highlighted in examining the normative samples that were used to compare levels of stress seen in this sample. On both the DSI and PSI, levels of stress as reported by participants were lower than those in normative samples. While there are not normative samples of parents of children undergoing BMT or hospitalization, or even with a chronic illness, the relatively low levels of stress reported by this sample highlights the need for the use of either more appropriate normative samples or more sensitive (i.e., situation-specific) measures.

While the intervention was designed to decrease stress in parents, several components (i.e., communication, coping) involved or were focused on the participants' relationship with her child. Despite the intervention's aim to assist parents' through the hospitalization, given the association between parent and child functioning (Melamed & Ridley-Johnson, 1988), measuring the child's adjustment or level or stress and/or anxiety may have lent additional support to the efficacy of the intervention.

As described in the Results section, the Strategies Checklist was administered to therapists of families participating in this study who were receiving additional

psychological services. While this served to provide some information about possible study confounds, the measure was simplistic and did not capture much of what may have been targeted during psychological treatment. Collecting more information relevant to outside treatment would have been useful. Although group size was quite limited, exploratory analyses were conducted to examine differences between participants followed by the psychology service ($n = 7$) versus those not receiving services ($n = 14$). Several similar effects for Time were noted, however, no significant group differences emerged. While providing additional psychological services not related to the current study is a clear confound of the investigation, it would not have been ethical, or even possible (the psychology service had an established relationship with the BMTU), to withhold such services. This confound represents one of the many challenges when conducting research within a clinical setting.

Intervention

The group difference in Strategy use and expected differences in several WCQ subscales suggest that participants in the Intervention condition were using concepts considered to be important when designing the intervention. Although the literature does suggest that these positive or problem focused coping strategies are related to better management of stress and/or adjustment (Lazarus & Folkman, 1984; Melamed, 1992), the specific mechanism has never before been examined in a prospective study of parents of children undergoing BMT. While the lack of group differences on measures of stress may be related to measurement issues as described above, it is also possible that the intervention did not target areas relevant to parents' stress while their children undergo BMT. Components of the intervention therefore simply may not have been particularly

effective in decreasing stress in these families. However, the three components considered important by Hunsberger et al. (1984) when targeting BMT families were included in intervention sessions. Given that the intervention was designed for use with a wide range of parents (i.e., with children of varying illness lengths, having done different amounts of background reading, etc.), many portions of the session were quite simplistic. Reexamining areas of reported stress in conjunction with intervention components would be an important step in designing future interventions.

Other issues related to the intervention include the one session format and the timing of administration. Although one session interventions have been effective in other investigations (Campbell et al., 1995; Jay & Elliott, 1990; Zastowny et al., 1986), it may not be adequate for this population. This may be particularly true for parents who are very stressed during the pre-transplant period. It may be difficult to comprehend information presented during this time, especially if it is to be used for some future point. Similarly, time of administration of the intervention varied. The size of the current sample does not allow for examining differences in the timing of the intervention. Future studies should attempt to more closely examine such differences.

One reason for the use of a one-session intervention was to limit the burden on participants. However, helping participants remember and use intervention techniques throughout their child's hospitalization was an important consideration in the development of this study. This was attempted through the use of the Strategy checklist, which was thought to provide a subtle reminder of possible ways to impact level of stress. However, use of the checklist for this purpose was not assessed. Anecdotally, mothers were not noted to comment on possible techniques they either may have used, or would

consider using again in the future, during completion of the checklist. A more formal reminder system could have been instituted such as standardized feedback during weekly administration of measures, or even through the use of phone calls (Campbell et al., 1995).

While participants did not formally indicate their beliefs about the intervention as a preparation for their BMT experience, parents in the Intervention condition were asked about their preparation. Most parents informally stated that they felt adequately prepared for the process. In addition, similar to the Jay & Elliott (1990) intervention, the majority of mothers in this sample reported that they found the relaxation component to be the most beneficial.

Future Directions

Further examination of the variables studied in this investigation is warranted. Using different measures that are more appropriate for this population will provide additional information regarding parents' stress as it relates to the BMT experience. The first step in continuing this line of research may therefore be designing more situation-specific and psychometrically sound measures. Only once appropriate measures have been identified can further research with these variables be conducted.

One important component of this area of research is longitudinal or follow-up data collection. The experience of BMT, and cancer treatment in general, impacts families for a long time after the actual process has ended (Kazak et al., 1997; Kupst, 1992). It is therefore essential to investigate how these families are doing after their experience in the hospital has ended. As noted earlier, several investigators are currently examining PTSD

symptomatology in childhood cancer survivors and their parents. Such symptomatology can best be examined through follow-up investigations.

Finally, once additional information pertaining to the stress experience has been gathered, a similar intervention administered under more stringent methodology would be appropriate. Parents of children undergoing BMT are clearly stressed prior to their child's hospitalization, and interventions can be designed to specifically ameliorate this stress. The field of pediatric psychology is relatively young, and much descriptive information is still needed to further our understanding of various medical conditions and related psychosocial processes. However, in order to advance the field, there must be equal emphasis on the development of interventions for those situations for which difficulties have been documented. There has been a call for continued investigation of interventions within the field of pediatric psychology (Drotar, 1997).

The intervention could take place earlier in the process as suggested by the data, targeting the pre-transplant versus post-admission phase. Such an intervention may incorporate home work assignments with planned follow-ups or even "booster" sessions. One important component to future interventions is the use of a "consumer satisfaction" questionnaire, formally measuring aspects considered to be most beneficial.

APPENDIX

Assessment Timeline

Measure	Baseline	Day -7*	Day 0*	Day +7*	Day +14*	Day +21*
Demographics	X					
Life Experiences Survey	X					
Ways of Coping Checklist	X					X
Daily Stress Inventory	X	X	X	X	X	X
Parenting Stress Index	X					X
Semi-structured Interview	X	X		X		X
Knowledge	X	X				
Adherence to Intervention Strategies		X	X	X	X	X
Illness Severity: BMTU		X	X	X	X	X
Parent Perception	X	X	X	X	X	X

Note: * refers to number of days pre or post-transplant. Participants completed the DSI on three randomly selected days each week of the child's admission, for a total of 14 administrations. Mother's perception of their child's illness severity was also assessed three times weekly, and coincided with completion of the DSI.

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BIOGRAPHICAL SKETCH

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I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.
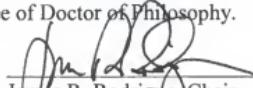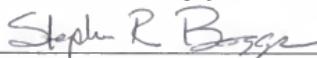
James R. Rodrigue, Chair
Associate Professor of Clinical and Health Psychology

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.
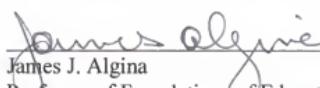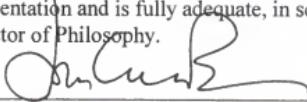
James J. Algina
Professor of Foundations of Education

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Stephen R. Boggs
Associate Professor of Clinical and Health Psychology

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John Graham-Pole
Professor of Clinical and Health Psychology

I certify that I have read this study and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.

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This dissertation was submitted to the Graduate Faculty of the College of Health Professions and to the Graduate School and was accepted as partial fulfillment of the requirements for the degree of Doctor of Philosophy.

August 1998

Dean, College of Health Professions

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